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**Support Needs and Service Provision for Family  
Carers from Black and Minority Ethnic  
Communities within the United Kingdom.**

**Nicholas Johl**

This thesis is submitted in partial fulfilment of the  
requirements of the degree of  
Doctor in Clinical Psychology

Coventry University, Faculty of Health and Life Sciences and  
University of Warwick, Department of Psychology

May 2013

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## **Declaration**

I declare that this thesis is my own work based on collaborative research and that the thesis has not been submitted for another degree at another university.

Authorship for the prepared thesis chapters are Nick Johl, Dr Tom Patterson and Dr Lesley Pearson.

The literature review will be submitted to the Journal of Dementia. The empirical study will be submitted to the Journal of Ethnicity in Substance Abuse and the reflective paper will be submitted to the Clinical Psychology Forum.

## **Summary**

Chapter one is a literature review of the experiences of carers from Black and ethnic minority communities caring for someone with dementia in the United Kingdom. Critical analysis of eight articles revealed that carers viewed symptoms of dementia as a normal process of ageing. Furthermore, the carers perceived their role as an extension of an existing responsibility to provide care and support for their family member. The literature review highlighted the majority of carers being female and stigma of a family member having a mental health issue still influenced carers' willingness to engage in formal health services.

Chapter two is an exploration of the experiences that staff within alcohol services have had whilst providing support to relatives of alcohol dependent individuals from the Sikh community. Ten staff members were recruited to take part in semi-structured interviews. Thematic analysis was conducted on the derived data, eliciting a number of themes illustrating the nature of familial support provided for someone who is alcohol dependent, the pro-social attitude towards alcohol held by Sikh family members, a lack of understanding regarding addiction and the confidential nature of alcohol services. This article provided evidence of inter-generational differences between Sikh family member's knowledge of addiction and the expectation of alcohol services. Lastly, the present study identified variations in how alcohol services target and tailor their services in specific ways to meet the needs of Sikh family members of someone with alcohol dependence.

Chapter three is a reflective article on the process of conducting the empirical research. The article addressed reasons why the lead researcher conducted research in this area and considers the effects of participant experiences of working with Sikh family members of someone with alcohol dependence. This chapter also discusses the lead researcher's relationship with participants and how the research process impacted on the lead researcher's personal life.

## **Abbreviations**

**UK**

United Kingdom

**BME**

Black Minority Ethnic

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**Chapter One: What do we know about the attitudes,  
experiences and needs of Black and minority ethnic  
carers of people with dementia in the United Kingdom?  
A systematic review of empirical research findings.**

Word count (excluding title, table and references): 7,900

Article prepared for submission to Journal of Dementia.

(Refer to Appendix 1 for submission guidelines)

## **1. Abstract**

This paper reviews recent literature on the experiences, attitudes and needs of caring for someone with dementia in Black and minority ethnic communities in the United Kingdom. Eight articles, which investigated carer experiences from Black and minority ethnic communities when caring for someone with dementia, were critically appraised. All eight studies used a qualitative methodology. The review identified several themes and issues across the qualitative studies. These included memory loss being viewed as a normal process of ageing, care being perceived as an extension of an existing responsibility, a poor understanding of what support services provide, the influence of migration, the impact of stigma, and increased female responsibility. Methodological limitations of the research literature studies are also highlighted and clinically relevant implications are discussed, alongside recommendations for future research in this area.

*Keywords:* Black, Minority, Ethnic, Carer, Dementia



## **2. Introduction**

### ***2.1 Prevalence of dementia among Black and minority ethnic communities***

Dementia is a major cause of disability in modern day society with approximately 800,000 people with the disease in the United Kingdom (UK) (Department of Health, 2009). This number is projected to double over the next 30 years with a cost to the economy greater than that for heart disease and cancer combined, despite most of the care being provided by family and friends (Luengo-Fernandez, Leal, & Gray, 2010). This predicted increase in the number of people with dementia is expected to be greater in Black and minority ethnic (BME) communities, as first-generation Afro-Caribbean and South Asian migrants enter the age groups with the highest incidence of dementia (Weimer & Sager, 2009).

A study by Knapp and Prince (2007) also suggests that although BME communities tend to have a relatively young age profile at present, this will change as a consequence of immigration patterns in the latter part of the 21st century, leading to significantly higher numbers of members from these communities with dementia. Furthermore, there is concern that mental health services are not well equipped to meet the needs of BME elders and their families (Lievesley, 2010).

## ***2.2 Carers in the UK***

Policy initiatives found in many western countries prioritise early diagnosis of dementia in order to facilitate timely access to treatment, information and support for people with dementia and their families (Department of Health, 2009). In the UK, around two-thirds of older people with dementia are supported in the community, and family carers are the most important source of dementia care. A family carer is an individual providing assistance to a relative who is experiencing difficulties due to physical, emotional or cognitive impairments, often without financial compensation (Bridges, 1995). There are approximately six million family carers in the UK, with as many as three in five people likely to become a carer in their lifetime.

Afro-Caribbean and South Asian communities represent the largest BME communities in the UK, yet the evidence base regarding dementia care in these communities is extremely limited. People from BME communities comprise 15% of the English population and 39% of the London population (National Audit Office, 2007). Although they access primary care at a similar rate to the indigenous population, they are less likely to access mental health services (Livingston, Leavey, Kitchen, Manela, Sembhi, & Katona, 2001). Research also points to significant variation among BME communities with regard to their motivation to adopt the carer role, their willingness to care, the experience of being a carer, and the use of external support (Parveen, Morrison, & Robinson, 2011).

### ***2.3 Rationale***

A previous review of literature into caring for individuals with dementia in Black and South Asian communities in the UK was carried out by Milne and Chryssanthopoulou in 2005. The review found that the consequences of care giving in Black and South Asian communities were significant but also different from those experienced by White carers. These consequences were seen to be mediated by factors including religion, conceptualisations of dementia and expectations of family duty. The review also highlighted an evidence base characterised by small scale studies and weak methodology which further undermined the validity of results.

Although the review by Milne and Chryssanthopoulou (2005) presented a series of findings in relation to the experiences of caring for a person with dementia in Black and South Asian communities in the UK, a number of limitations were apparent. Firstly, the review included studies conducted in the USA to supplement those found in the UK, thereby not focussing on Black and South Asian communities in the UK alone. Due to both cultural differences and variations in healthcare systems it is difficult to generalise findings from Black and South Asian communities in the USA and attribute these to the UK. A further limitation of the review is its focus upon the experiences of only two BME communities in the UK, namely Black and South Asian; thereby limiting the knowledge of caring experiences held in other BME communities which reside in the UK.

An updated review of literature is warranted in order to gain a better understanding of the experiences, attitudes and needs of caring for someone with dementia in Black and South Asian communities and to build upon the existing findings of Milne and Chryssanthopoulou (2005). The present literature review will build on these findings by exploring the experiences of all BME communities within the UK. This will allow for a more focussed critical evaluation of empirical findings from research into the experiences, attitudes and needs of caring for someone with dementia among BME communities.

#### ***2.4 Aims***

Given the paucity of literature about the experience of carers from BME communities, there is a need to understand the evidence base surrounding the experiences, attitudes and needs of these individuals. The profound effect of culture and ethnicity on caregiving underlines the importance of addressing the cultural context of a carer experience.

The present literature review aims to provide a critical appraisal of empirical research into the attitudes, experiences, and needs of these individuals providing care for a person with dementia within BME communities in the UK.

### **3. Method**

A systematic literature search was conducted by using six internet databases (PsychARTICLES, PsychINFO, Medline, CINAHL, Web of Knowledge and Scopus) to find peer reviewed journal articles (between 2005 and 2013) which examined the experiences, attitudes and needs of people from BME communities caring for someone with dementia. The databases were searched

using key terms (see Figure 1. below). The terms were searched in journal article abstracts, titles and keywords. The overall search resulted in 25 peer reviewed articles, all of which were screened against the following criteria for inclusion in the present review:

### ***3.1 Inclusion Criteria***

1. Papers published between 2005 and 2013.
2. The study explored the attitudes, experiences or needs of carers providing care for a family member suffering with dementia.
3. The carers were from a Black or minority ethnic community.
4. Participants were recruited within the UK.
5. The study was published in a peer-reviewed journal.

### ***3.2 Exclusion criteria***

1. Unpublished dissertations or non-peer reviewed articles.
2. Articles published prior to 2005.
3. Non UK based studies.
4. Quantitative and survey based articles.

**Figure 1.** Key search terms

<b>South Asian, Black, Muslim, Hindu, Sikh, Irish, Afro-Caribbean, Eastern European, ethnic, minorit*,bme,</b>
<b>And</b>
<b>Carer, cargiv*,</b>
<b>And</b>
<b>Dementia, Alzheimer's,</b>

Once relevant articles were identified, their reference lists were searched using the same search terms for additional articles. The final search was conducted in March 2013 and no additional articles were identified. Eight articles were found to meet the required criteria for inclusion in the present review. Table 1 presents a summary of the studies, indicating the sample size, the characteristics of sample and the main findings. Figure 2 shows a flow diagram of the literature review article search process.

**Figure 2.** Literature review search flow diagram

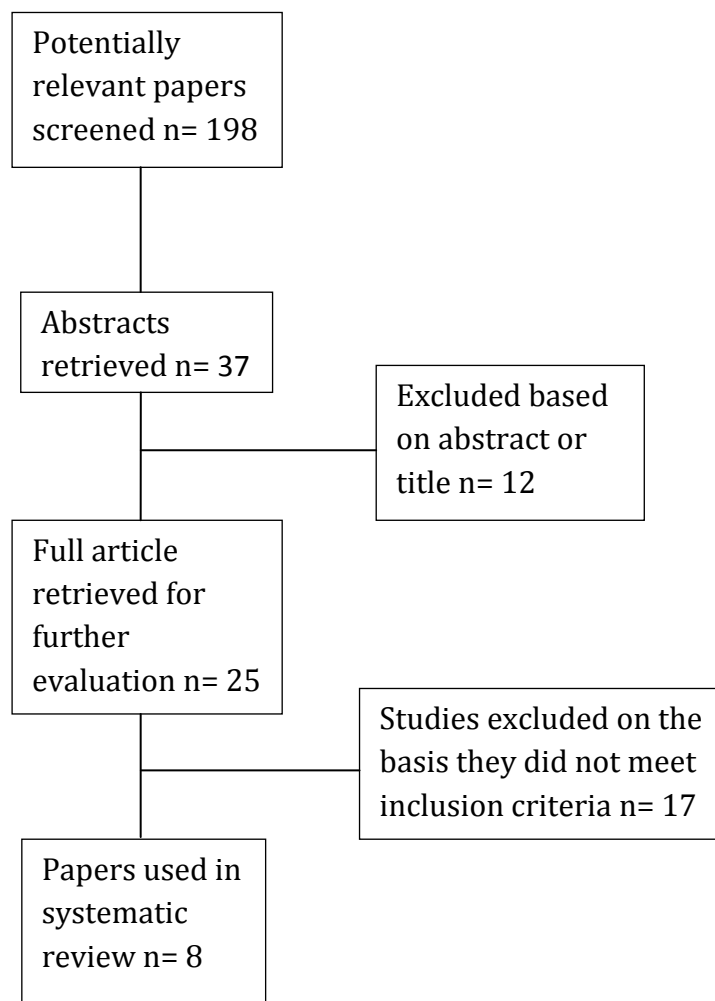


Table 1. Summary of reviewed articles

Study	Aim	Methodology	N	Sample	Design	Main findings	Limitations
Adamson and Donovan (2005)	Examining the experience of caring for an older family member, focusing on minority ethnic carers of a person with dementia.	Qualitative (grounded theory)	36	Age range - not stated Gender - not stated Ethnicity- 15 South Asian 21 Afro-Caribbean Geographical location-	In-depth semi-structured interviews	Experience of informal care has many similarities to the experience of chronic illness. Carers describe their caring role in terms of: A continuation of their previous relationship with the person being cared for. The participants also describe highly disruptive elements to change in the relationship. Participants saw caring as a virtuous state and therefore seen as the "normal" thing to do.	The majority of participants in the study were female. The sample recruited were already accessing mental health services. The study used different interpreters used throughout interview stage. Only carers from two BME groups were included in the study.
Botsford, Clarke and Gibb (2011)	Examining the experiences of partners of people with dementia in two BME groups.	Qualitative (grounded theory)	13	Age range- 60-80 Gender- 6 male 7 female Ethnicity- 7 Greek Cypriot 6 Afro-Caribbean Geographical location- London	43 In-depth interviews conducted over an 18 month period between 2007 and 2009	Participants engaged in an on-going process of "redefining relationships". Greek Cypriot partners tended to emphasise family relationships. Afro-Caribbean partners tended to view themselves primarily as an individual or as part of a couple. Participants accommodated the changes associated with dementia into their lives rather than seeking help. Participants saw their experience as an extension of their responsibilities as a husband, wife or partner. There was a universal lack of awareness of symptoms of dementia.	The study took place in only one city which limits generalising of results to other BME groups in other areas of the UK. Only 1 <sup>st</sup> generation migrant carers were recruited in the study. Only "partners" of dementia sufferers were recruited to take part in the study.

<b>Study</b>	<b>Aim</b>	<b>Methodology</b>	<b>N</b>	<b>Sample</b>	<b>Design</b>	<b>Main findings</b>	<b>Limitations</b>
Jolley, Moreland, Read, Kaur, Jutlla and Clark (2009)	To learn about dementia within BME groups and how to improve relevant services.	Qualitative (not stated)	30	Age range- not stated Gender- not stated Ethnicity- 10 Afro-Caribbean 20 South Asian Geographical Location- Wolverhampton	Interviews conducted over a six year period between 2000 and 2006	There was a continuing lack of knowledge and understanding of dementia among carers. Lack of understanding led to stigmatisation, mistaking symptoms of dementia with old age. Carers remain isolated. Variability in knowledge and attitudes between families and between generations. Existing services are seen to lack cultural awareness.	The study was only conducted in one location. In the second stage of the study, only Sikh carers of someone with dementia were interviewed and no Afro Caribbean carers were used. The study only focused on two BME groups in the UK.
Jutlla (2010)	Understanding migrant Sikh carers caring for an older person with dementia.	Qualitative (grounded theory)	12	Age range- not stated Gender - 3 male 9 female Ethnicity - Sikh Geographical Location- Wolverhampton	2-3 narrative interviews	Participants viewed their caring role as an extension of an existing obligation and identity. Migration experiences did impact on experiences of carers. Participants idealised their societies of origin, including type of support available to them in that society.	The study was only conducted in one city. The study only focused on carers of someone with dementia from a Sikh community. Therefore, findings can only be generalised to carers who have migrated to the UK.



<b>Study</b>	<b>Aim</b>	<b>Methodology</b>	<b>N</b>	<b>Sample</b>	<b>Design</b>	<b>Main findings</b>	<b>Limitations</b>
Jutla and Moreland (2009)	Understanding Sikh carers caring for an older person with dementia	Qualitative (not stated)	5	Age range - not stated Gender - not stated Ethnicity - Sikh Geographical Location- Wolverhampton	Interview	Sikh community is not a homogeneous group. Diversity and differences within the Sikh community can have important implications for care. Factors to be considered include: carer's country of origin; migration route and reasons for migration. Services must be flexible and appropriate to carer situation.	Due to the low sample size, results cannot be generalised to all BME carers of someone with dementia. The findings of only two interviews were presented and discussed in the study. The study only focussed on carers from a Sikh background. The study was not conducted in more than one location.
Lawrence, Murray, Samsi and Banerjee (2008)	To explore the caregiving attitudes, experiences and needs of family carers of people with dementia from the three largest BME groups in the UK.	Qualitative (grounded theory)	32	Age range - 33-87 Gender - 7 male 25 female Ethnicity - 10 Afro-Caribbean 10 South Asian 12 White British Geographical Location- London	In-depth individual interviews	Carers were identified as holding a 'traditional' or 'non-traditional' caregiver ideology. Participants conceptualised caregiving as natural, expected and virtuous. This informed feelings of fulfilment, strain, carers' fears and attitudes towards formal services. Majority of the South Asian, half of the Afro-Caribbean and a minority of the White British participants were found to possess a traditional ideology.	The majority of participants were female which limits the results being generalised to male carers of someone with dementia. The study was only conducted in London. Only carers born in the UK were used in the study. The study recruited carers from just two BME groups. Namely South Asian and Afro Caribbean carers.

Study	Aim	Methodology	N	Sample	Design	Main Findings	Limitations
Mackenzie (2006)	To identify the support needs of family carers from Eastern European and South Asian groups	Qualitative (thematic analysis)	18	Age range - not stated Gender - not stated  Ethnicity - 11 Pakistani 5 Indian 1 Polish 1 Ukrainian  Geographical location - northern English city"	Semi-structured interviews	Understanding of dementia differed between Eastern European and South Asian carers. The understanding of dementia in different cultural contexts caused stigma. The management of stigma between eastern European and South Asian carers was similar. The experience of stigma influenced engagement with formal and informal support.	The study was unclear if participants had migrated to the UK or were born in the UK. The carer's relationship to the dementia sufferer was not stated in the study. Unclear use of the term South Asian limited the generalisation of findings. A small sample size of Eastern European participants further limited generalisation of results.
Mukadam, Cooper, Basit and Livingston (2011)	To explore the link between attitudes to help-seeking for dementia and the help-seeking pathway in minority ethnic and indigenous groups.	Qualitative (grounded theory)	18	Age range - 27-85 Gender - 5 male 13 female  Ethnicity - 4 White 5 Indian 5 Black 1 Irish 1 White other 1 Chinese 1 Asian other  Geographical Location- London	Semi-structured interviews	Minority ethnic carers tended to delay help-seeking until they could no longer cope or until others commented on the problems. Dementia symptoms were seen as a normal part of ageing. Carers thought that families should look after their own elders. Minority ethnic carers held certain beliefs about the etiology of cognitive impairment, psychiatry and their sense of familial responsibility which affected their level of engagement with formal services.	The majority of participants were female. The study was conducted in only one city. The carers recruited for the study were already accessing formal health services in relation to their family member with dementia.

## **4. Results**

All eight peer reviewed articles included in the present review used a qualitative methodology, with five of the articles analysing their data using grounded theory. The majority of studies used semi-structured interviews to guide data collection. The age range of the carers included in the present literature review ranged from 27 to 86 years. Six of the articles focused on the experiences of more than one BME community, while two articles focused on only one BME community. The studies explored various psychological and social factors which influenced the experience of caring for a family member with dementia in the UK.

The findings from the present literature review will be framed in the following themes; perception of dementia as a normal process of ageing, caring seen as an extension of an existing responsibility, perception of existing mental health services, impact of migration on the caring role, impact of stigma on a carer's role, and female responsibility to provide care for a family member with dementia.

### ***4.1 Perception of dementia as a normal process of ageing***

Evidence from the literature reviewed highlighted that a number of carers from BME communities had culturally based perceptions of dementia. Botsford, Clarke, and Gibb (2011) conducted 43 in-depth interviews with 13 Greek Cypriot and Afro-Caribbean carers aged between 60 and 80 years, caring for a family member with dementia in London. The study took place over an 18 month period (2007-2009) and the data was analysed using a grounded theory

approach. It was found that most of the participants had interpreted the changes associated with dementia as part of a normal process of ageing. This was expressed through participants describing that memory problems were supposed to occur when a person became old. The majority of participants expressed a general belief that cognitive decline might be expected and therefore forgetfulness was part of the ageing process (Botsford et al., 2011).

Botsford et al., (2011) also found that the perception of memory problems being perceived as a normal process of ageing was associated with a delay between carers noticing a problem and seeking an explanation. The study highlighted a specific way in which dementia is construed in two BME communities. However, these findings are limited to only two discrete Greek Cypriot and Afro-Caribbean communities in London.

This finding that carers viewed their family member's cognitive decline as a normal process of ageing was mirrored in a study by Jolley, Moreland, Read, Kaur, Jutlla, and Clark (2009) who conducted interviews over a six year period with 30 BME carers of people with dementia in Wolverhampton. The study highlighted that a lack of information and understanding held by Afro-Caribbean and South Asian carers with regard to dementia led them to be unaware of its differentiation from normal ageing. Carers were found to not seek help or access mental health services due to being unaware that they were caring for someone with dementia (Jolley et al., 2009).

#### ***4.2 Caring as an extension of an existing responsibility***

As noted previously, a number of carers viewed cognitive decline as a normal process of ageing and therefore did not see their family member as suffering from a specific mental health disorder such as dementia. In addition to this, several studies highlighted how carers from BME communities typically saw their role as an extension of an existing responsibility to care for their family member with dementia.

For example, Adamson and Donovan (2005) interviewed 36 carers from Afro-Caribbean and South Asian communities who were caring for a family member with dementia across numerous geographical locations in the UK. Through the use of in-depth, semi-structured interviews, the study aimed to discover the meaning of being a carer for a family member. Using a grounded theory approach to analyse interview data, the study highlighted that participants viewed caring as a normal feature of their life which was often a continuation of their identity. It was found that participants did not view themselves as “carers”, but rather as fulfilling a natural role within the family (Adamson & Donovan, 2005).

The perception of caring as an extension of an existing responsibility was also evident in a qualitative study which compared the experiences of White, Afro-Caribbean and South Asian carers, all caring for a relative with dementia. In-depth individual interviews with 32 carers, aged between 33 and 87 years from London, found that those carers with “traditional caregiver ideologies” saw caring as natural, expected and virtuous. Holding strong religious values motivated and shaped a carer’s desire to support a family member. In particular,

daughter and son carers of South Asian origin were most likely to explain this in terms of caring as a cultural norm and as an opportunity to reciprocate parental support. This account was absent from the accounts of White British sons and daughters caring for their parents in the study (Lawrence, Murray, Samsi, & Banerjee, 2008).

The study also found that Afro-Caribbean carers who were born in the UK, (second or third generation) held less traditional views of caring for an elder than first generation Afro-Caribbean carers (Lawrence et al., 2008). This finding suggests that within BME communities, there are differences depending on the generation of the carer, although a limitation is that participants were only from the London region, and therefore, not necessarily representative of BME communities in other areas of the UK.

This finding of caring being a culture bound phenomenon was supported by research reporting that carers with strong family centred beliefs saw caring as a natural responsibility (Botsford et al., 2011). Similarly, previous research has also described a tendency of some carers to frame their role as a natural and expected facet of married life (Lawrence et al., 2008). In a similar vein, Adamson and Donovan (2005) found that carers often viewed the caring role as an accepted part of their relationship with the family member with dementia and viewed it as an extension of their family responsibilities. However, despite highlighting how carers situate their role as a cultural norm, Adamson and Donovan (2005) did not investigate what factors might account for this being the case.

### ***4.3 Perception of existing mental health services***

As noted previously, research has found that carers from BME communities may see dementia as a normal process of ageing and appear to see their role as an extension of an existing responsibility. Research has also found that some carers had distinct perceptions of existing mental health services. Jolley et al. (2009) for example, conducted a number of interviews over a six year period (2000-2006) with 30 carers from the Afro-Caribbean and South Asian community in Wolverhampton. The main findings from these interviews revealed that carers perceived mental health services to lack the confidence and competence to address language barriers and cultural differences. This resulted in the carers feeling culturally stereotyped (Jolley et al., 2009).

In addition, the study by Jolley et al. (2009) captured the experiences of these carers whilst visiting their local General Practitioner. The majority of carers felt that the knowledge base of General Practitioners was variable, leading to some cases of initial misdiagnosis or a delay in reaching specialist care and support. Carers from the study also highlighted a distinct lack of clarity regarding the eligibility criteria for accessing mental health services. This resulted in carers feeling that they were not eligible to access such services (Jolley et al., 2009). Although this study was able to highlight the experiences of carers accessing mental health services for support, a limitation is that in the latter stages of the study, only South Asian carers were interviewed and no Afro-Caribbean carers were involved as seen in the initial interviews conducted. This results in no comparable data available with regard to the Afro-Caribbean carers.

Another distinct perception of mental health services held by carers was captured by Mukadam, Cooper, Basit and Livingston (2011). Using semi-structured interviews with 18 Afro-Caribbean and South Asian carers, the study found that a lack of trust in the healthcare system affected their experience of caring for someone with dementia. This lack of trust was also aligned with a perception that mental health services could only offer a diagnosis of dementia rather than treatment, intervention or general support. For many carers, a diagnosis would not change their circumstances and therefore, was not perceived as useful (Mukadam et al., 2011).

#### ***4.4 The impact of migration on the caring role***

It is noteworthy that some carers from BME communities appear to have distinct perceptions of what existing mental health services can provide. For some carers, mental health services were experienced as untrustworthy, having variable knowledge of dementia and only able to provide a diagnosis and nothing further. An additional finding which developed throughout the present literature review was the impact of migration on the caring experiences of BME carers. Jutlla (2010) conducted 2-3 narrative interviews with 12 carers from a Sikh community in Wolverhampton about their experiences of caring for a family member with dementia. Utilising a grounded theory approach to analyse the narrative interviews, Jutlla (2010) found that the migration route of Sikh carers influenced their role. The study coined the process of migration as a “repositioning of existence” which occurs when someone migrates to another country and culture. The study suggests that when caring for a family member with dementia, BME carers experience a further episode of “repositioning of



existence” which may manifest itself in adopting new responsibilities and also a role repositioning from a husband or wife to that of a carer (Jutlla, 2010).

The study also found that carers who had migrated to the UK often held narratives of how support would be “back home”. Referred to as “idealised narratives of situations and perceptions pre and post migration”, carers would idealise their societies of origin in relation to the presence of an extensive family network and community support. Although the carers acknowledged the improved health and social support services available in the UK, they still expressed a desire for their caring role to be located in their country of origin (Jutlla, 2010).

A study by Jutlla and Moreland (2009) also identified the influence of migration on Sikh carers. Interviewing five Sikh carers of a family member with dementia from Wolverhampton, it was revealed that within the Sikh community, there was a range of different experiences of migration to the UK. The study revealed how different migration routes, age at which a person migrated, and the reason for the migration influenced their caring experience (Jutlla & Moreland, 2009).

Presenting the findings of only two out of five participants interviewed, the study by Jutlla and Moreland (2009) captured differences in migration experiences. One carer had only recently immigrated to the UK due to marrying a UK born Sikh male. For this carer, her experience was one of isolation and lack of support from the community around her and a huge contrast to the support available if providing care in India. This experience contrasted with that of a male carer who came to England in the 1960s and lived with other young men whilst seeking employment. During this time the carer learnt how to cook, clean,

be self-sufficient, and it was these skills learnt when first immigrating to England which were then used when he began caring for his wife with dementia (Jutlla & Moreland, 2009).

This concept of migration influencing a carer's role is supported further by Botsford et al. (2011) who conducted 43 interviews with 13 carers from Greek Cypriot and Afro-Caribbean communities in London. Using the term "shielding process", the author identified a concept of resilience held by the carers from a BME community. This was believed to be due to the carer having to overcome important challenges and obstacles whilst settling into a new country of residence. Thus the carers had already developed ways of coping and possessed a number of resources to draw upon which came into play in their present situation of caring for a family member with dementia (Botsford et al., 2011).

These two studies (Jutlla, 2010; Jutlla & Moreland, 2009) have highlighted some very noteworthy findings with regard to the impact of migration on a carer's role. However, a limitation of the study by Jutlla and Moreland (2009) is the small sample size of Sikh carers which limits generalisability of results. Furthermore, by concentrating on only one BME community, the findings can only be related to members of the Sikh community who have in fact migrated. It is predicted that a number of carers from the Sikh community will not have migrated and may therefore have a very different experience of caring for a family member with dementia. In addition, for carers born in the UK, they may have little knowledge of the systems of support available in their ancestral country of origin.

#### ***4.5 Impact of stigma on a carer's role***

The impact of stigma is a phenomenon that has been widely reported with regard to BME communities accessing mental health services (Taha & Cherti, 2005). The experience of stigma when caring for a family member with dementia was present in the findings of a study by Mackenzie (2006) who carried out semi-structured interviews with 18 carers from Eastern European and South Asian communities in a northern English city. Through thematic analysis of interviews, the author found that stigma was present in both cultures.

East European carers, caring for a family member with dementia experienced stigma from within their own community. This led to a number of carers to not seek help from fellow members of their community and instead described "hiding" the person with dementia whilst beginning to sever ties with family and friends. This process of isolation was seen as an inevitable outcome in trying to limit stigma. Furthermore, this fear of stigma was also present in relation to other mental health problems (Mackenzie, 2006).

Remaining with this study, the construct of stigma was also encountered by carers from a South Asian background. South Asian carers viewed dementia as a mental health issue caused by spiritual influences. Such explanations imposed a level of stigma on the family and dementia sufferer, which led carers to act in a similar way to the Eastern European carers by concealing the person with dementia from the rest of the community.

A similar concept of stigma featured in the findings of Mukadam et al. (2011) who assessed why ethnic elder carers present later to dementia related health services. By interviewing 18 carers, it was found that stigma was a barrier to accessing support from mental health services only for BME carers. The fear of stigma was not present in White carers interviewed for the study (Mukadam et al., 2011).

Overall, the findings of Mackenzie (2006) highlight a fear of stigma that is found in other aspects of mental health experiences among BME communities (Knifton, Gervais, Newbigging, Quinn, Wilson, & Hutchinson, 2010). However, a limitation of Mackenzie's (2006) study is in relation to the sample. A lack of understanding of cultural differences between different sub groups of the South Asian population was found in this study. Taking into account culture specific beliefs, the study reports findings in relation to Pakistani carers viewing dementia as "evil spirits" and being a "curse" on their family. This phenomenon is very common in Pakistani cultures but not as prevalent in Sikh and Hindu cultures (Khalifa & Hardie, 2005). Therefore, this explanation for what they perceived to be the cause of dementia should have been limited to the experience of Pakistani carers rather than suggesting it has relevance for Sikh and Hindu carers as done in this study. This indicates the importance of knowledge and awareness of the various BME communities when research is conducted in the UK.

#### ***4.6 Female responsibility***

A final issue found throughout the articles reviewed was the responsibility of care provision falling predominantly on female carers from BME communities. For example, Jutlla and Moreland (2009) found that when providing care for someone with dementia in a Sikh household, there was an expectation for the daughter in-law to provide the care. These researchers found that this example added to the already high incidence rate of daughter in-laws remaining as “hidden” carers in Sikh families.

The presence of female care responsibility featured in a second study by Jutlla (2010), conducted with Sikh carers in Wolverhampton. Whilst assessing the impact of a carer’s migration to the UK on their caring experience it was also found that females in particular held an existing care identity. This would suggest that females in particular, may already have been providing a caring role for the person with dementia. Furthermore, this was in contrast to male carers who exhibited a change of their current identity into a caring role which they had not previously identified with (Jutlla, 2010).

A similar finding was present in a study by Adamson and Donovan (2005) who interviewed 21 Afro-Caribbean and 15 South Asian carers of a family member with dementia. This grounded theory study found that female carers felt a stronger moral obligation to care than the male carers (Adamson & Donovan, 2005). In line with these findings, Botsford et al. (2011) identified an expectation that daughters would provide care for the person with dementia. This tendency was found to be more prominent in a Greek Cypriot community than in an Afro-Caribbean community.

It is suggested that this is not an uncommon concept, with an increasing number of females caring for parents and parent in-laws in general (Hirst, 2001). These findings from Adamson and Donovan (2005) appear to relate to those of Botsford et al. (2011) and Jutlla (2010) in females holding an existing, moral obligation to care that may not be seen as much in male carers. However, what is unclear from the findings of these three studies, is whether this female care responsibility can be explained by gender differences, or is due to being part of a BME community.

## **5. Discussion**

The aim of the present review was to critically evaluate empirical evidence on the experiences, attitudes and needs of members of BME communities caring for a family member with dementia in the UK. The present review highlighted a number of complex and culture bound factors which characterised their experience of caring for a family member. These related factors were consistent findings across the majority of studies reviewed.

It was noted that the level of understanding of dementia impacted on the carers' experience. A number of carers viewed a decline in cognitive functioning as being a normal process of ageing. These findings are also consistent with a previous literature review by Milne and Chryssanthopoulou (2005) which identified that carers viewed symptoms of dementia as a normal process of ageing. This would imply that carers from BME communities continue to view the person they are supporting as presenting with symptoms of old age and not as someone with a medical condition that they should seek support for.

The majority of articles reviewed here found that, for a number of BME carers, their role was seen as a natural progression in their life, and a way of repaying the care they had received previously from the family member with dementia. In relation to whether or not carers from BME communities are likely to access mental health services for support, this finding suggests that carers may not identify a need for support from mental health services. However, further larger scale research is needed to adequately test this hypothesis.

The current review has also highlighted the value held by family members of being able to care for a relative with dementia. Lawrence et al. (2008) describes this value as an, "obligation to provide the care themselves", with a number of family members feeling that placing their relative with dementia in a care home would cause them to encounter stigma amongst their community or a feeling of failure. The findings of Botsford et al. (2011) also support the premise that caring for a family member with dementia should be completed by the family members themselves in BME communities. Furthermore, these findings also support a previous literature review which found that family members from BME communities in the UK, providing care for someone with dementia considered their role to be part of normal kinship responsibilities (Milne & Chryssanthopoulou, 2005).

In a similar vein, Mackenzie (2006), when interviewing carers of family members with dementia from an Eastern European community found that carers viewed, "keeping it in the family" as a very important value to adhere to. The participants placed particular value on familial responsibility to look after the person with dementia and that outside help was viewed as intrusive. This

would suggest that mental health services could improve by offering a type of support for carers which enable the person with dementia to be supported at home. This may help to minimise the risk of carers feeling stigmatised by other community members, and would allow them to complete their familial obligation to care for an elder.

The present review has highlighted a construct present in several qualitative studies which describes how migration of carers from BME communities has an impact on their caring experience. Evidence from these studies indicates that carers who migrated to the UK held a strong sense of resilience. This attribute seemed to assist first generation carers to manage the role and responsibilities of being a carer for someone with dementia without accessing mental health services for support. This would imply that services would benefit from being aware of the migration route of carers from BME communities and consider how this would impact on their desire to access mental health services for support.

Furthermore, the findings of Mackenzie (2006) were explicit in relation to the impact of stigma on a carer's experience. The fear of being stigmatised led carers to isolate not only themselves, but also the dementia sufferer. This could potentially lead to members of the community who are suffering and in need of specialist support from mental health services being isolated. This was not dissimilar to the finding by Milne and Chryssanthopoulou (2005) who found that carers felt stigmatised due to a family member having dementia. This would suggest that services need to consider providing education and psycho-education for BME communities on the nature of dementia as a lack of



understanding appears to continue to cause carers to feel stigmatised from other members of their community.

The present literature review has highlighted a general tendency for female family members to be the principal providers of care for family members with dementia. This particularly related to the main carer being a wife, daughter or daughter in-law being expected to take responsibility for caring for a relative. For many BME communities, it was a cultural norm for female family members to adopt this role more typically than their male counterparts. In some instances, the studies revealed that this cultural norm was an extension of an already existing obligation held by the female family members.

The findings from the present literature review are also in line with a previous review by Milne and Chryssanthopoulou (2005) which identified a cultural role among females from Black and South Asian communities to provide the majority of care for someone with dementia. This would suggest that the majority of carers of someone with dementia from BME communities in the UK are likely to continue to be female. Therefore, further qualitative research could usefully determine the extent to which mental health services are providing adequate support for female carers and whether this has implications for tailoring mental health services to support their needs.

## **6. Limitations**

The present review has identified a number of limitations of the existing evidence base. The first is the lack of male participants across most of the studies. The majority of existing published research provides an insight into the experience of how females cope with being a carer, which most likely represents the majority of carers for someone with dementia in BME communities. However, whilst bearing this in mind, we still lack an understanding of the male experience of caring in BME communities. Several of the studies reviewed here have acknowledged this limitation and recommend that further studies should assess the experience of male carers from BME communities. This is also a recommendation of the present literature review.

A specific limitation of the UK literature in this area is the pattern of the majority of participants being recruited from only one major city or different boroughs of London. Although this provides an insight into the experience of carers in these specific areas, it limits generalising findings to the wider UK. Considered together with the fact that the majority of research into this topic has, until now, relied on qualitative methodologies with small sample sizes, it is recommended that researchers should now start to build on the current evidence base with larger quantitative studies encompassing multiple sites in the UK, and including BME carers in more contexts.

A further limitation which has arisen from the present review is the number of ethnic sub communities which were grouped under the umbrella term of “South Asian”. A number of studies presented their findings using the term “South Asian” to express the experiences of Pakistani, Sikh and Hindu carers (Adamson

& Donovan, 2005; Mackenzie, 2006; Mukadam et al., 2011). Mackenzie (2006) for example, highlighted that Pakistani carers viewed their carer role as a means to gain 'blessings from god', whilst Sikh and Hindu carers described their role as 'repaying' the person with dementia for previous acts of kindness. These are two very different narratives underpinning why participants take on a caring role, and the author has grouped these practices as a "South Asian" experience.

This observation is reiterated by Jutla and Moreland (2009) who emphasise how BME communities are not homogenous, and there are differences of experience when caring for someone with dementia between these communities. It appears that when studies have adopted this "South Asian" labelling approach they have not adequately captured the full range of experiences, attitudes and needs of individuals from BME sub communities.

Interestingly, this limitation identified in the current literature review was also identified in a previous review by Milne and Chryssanthopoulou (2005) who criticised research in this area for using terms which were not clearly defined, resulting in a reduced validity of UK research. From the findings of this present literature review, there appears to be a continued lack of rigour in using appropriate terms to describe BME communities with regard to their experiences, attitudes and needs when caring for someone with dementia.

Overall this limitation has huge bearings on our understanding of the experience of carers from a BME community. By grouping a number of ethnic communities together, the ability to compare and contrast caring experiences, and assess whether different BME communities have different needs for mental health services is lost. At present, it is only possible to compare and contrast the

experiences, attitudes and needs between White, Afro-Caribbean and “South Asian” carers.

## **7. Implications for practice**

Although the research has highlighted how carers from BME communities experience caring in different ways from a White British community, it is evident that within BME communities, there are differences in the experiences, attitudes and needs when caring for a family member with dementia. This has been evident when comparing the experiences, attitudes and needs of Greek Cypriot with Afro-Caribbean carers and also when comparing Eastern European carers to those from a South Asian background (Botsford et al., 2011; Mackenzie, 2006). This has significant implications for mental health services. It means that services need to be aware of these cultural differences and tailor their services to accommodate the individualistic nature of BME communities in the UK.

With regard to changing immigration patterns in the UK, it would be predicted that mental health services will come into contact with carers from a wider range of BME communities in the future who will have their own individual perceptions and experiences of caring for a family member with dementia. Therefore, it would be essential for mental health services to be able to provide a meaningful, flexible and accessible service to these carers.

The findings from this present review have also found how many carers from BME communities viewed their role as an extension of an existing responsibility to provide support for their family member with dementia. This would imply

that carers from BME communities may be at risk of carer burden or stress when providing for this family member without assistance from formal care services. Therefore it is important that mental health services are supporting carers from BME communities with their own mental health and ensuring that carers are not suffering from any specific mental health difficulties due to the impact of their carer role.

A lack of knowledge appears to be a common thread among the research collected which would imply that mental health services need to be aware of existing beliefs held by carers with regard to dementia. This was particularly pertinent in findings by Mackenzie (2006) where carers from a Pakistani background believed symptoms of dementia to be an “evil spirit” which had consumed their family member. These beliefs would greatly impact on the experience of being a carer and on their intent to access mental health services. Therefore, it would be advisable for mental health services to aim to increase this knowledge of what dementia is for family members and also be aware of cultural beliefs held by BME carers.

However, it is also important to acknowledge how attempts to tailor mental health services to meet cultural needs can be misunderstood by members of a BME community. Rao (2006) raised the issue that service providers may lack confidence in producing specialist services in the worry of appearing racist or singling out a community. To limit this, perhaps mental health services would benefit from employing staff from a range of ethnic backgrounds with a number of language skills would be more appropriate.

If the employment of staff from a range of ethnic backgrounds could not be achieved, mental health services could also increase the knowledge of existing staff members in their service on the range of BME communities which exist in the UK through staff training. This would provide staff working in mental health services with the cultural awareness of certain BME communities and would assist them in understanding the cultural significance of being a carer for a family member with dementia within different cultures.

Finally, dementia related services may benefit from using initiatives adopted by other mental health services to increase the access and engagement of BME communities. Kaur, Jutla, Moreland, and Read (2010) for example, found that the use of a “link nurse” which was a community psychiatric nurse, who spoke Punjabi and English, and understood the relevant cultural issues, helped people from BME communities to gain a better understanding of mental health, thus increasing their level of engagement in mental health services.

## **8. Implications for future research**

It is clear from this literature review that there are a number of implications for future research. One implication is that future research in this area should address a gap in the literature in terms of capturing the experiences, attitudes and needs of male carers from BME communities. This would not only strengthen our knowledge of carers from BME communities in general, but would also add to the literature of how males experience being a carer for someone with dementia. Some of the studies in this present review have clearly identified how gender roles held in BME communities impact upon the

experience of being a carer (Adamson & Donovan, 2005; Botsford et al., 2011; Jutlla, 2010).

Further research would also benefit from examining the experience of caring in a range of geographical locations across the UK. The research included in this article has often been conducted in one major city where there is naturally a large proportion of one particular BME community. Widening the range of locations in which participants are recruited from would allow research to assess if there are any similarities or differences in carer experiences, attitudes and needs depending on geographical location.

Whilst conducting this present literature review, it was evident that very little research has been conducted on the largest BME community in the UK; namely the Irish community. Research has found that there are a number of “hidden” dementia sufferers from Irish communities in the UK who are not accessing mental health services for support (Tilki, Mulligan, Pratt, Halley, & Taylor, 2010). This would also suggest that there would be a number of hidden carers from this community.

Future research should aim to understand the experiences, attitudes and needs of this large and long established community to allow a broader understanding of the experience of caring for a family member with dementia among BME communities in the UK. This is also supported by evidence from the 2001 census which found that members of the Irish community have the highest proportion of elders among BME communities in England (Royal College of Psychiatrists, 2009).

## **9. Conclusion**

This paper reviewed the recent literature on the experiences, attitudes and needs of caring for someone with dementia in BME communities in the UK. The review found memory loss being viewed as a normal process of ageing among BME communities with the role of a carer being perceived as an extension of an existing responsibility. The review found that carers from BME communities were most likely to be female and that they held a poor understanding of what support services were able and what these services could provide.

The review also highlighted how a carer's migration to the UK affected their experience of caring for a family member with dementia. Furthermore, the review found that carers from BME communities continued to encounter stigma in relation to a family member suffering with dementia. This not only impacted on their carer experiences, but also impacted on their willingness to access formal mental health services for support.



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**Chapter Two: An exploration of alcohol services' staff experiences of providing support to relatives of alcohol dependent individuals from the Sikh community.**

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(Refer to Appendix 2 for submission guidelines)

### **11. Abstract**

The present study investigated the experiences of alcohol services' staff providing support to Sikh family members of alcohol dependent individuals. Ten staff members agreed to take part in semi-structured interviews. Thematic analysis of the interview data elicited themes illustrating the nature of familial support provided and attitudes to alcohol use. Participants identified Sikh family members as lacking an understanding of addiction and the treatment options available for addiction. Participants describe inter-generational differences between Sikh family members when accessing alcohol services for support. Lastly, participants highlighted ways in which alcohol services target and tailor their services to meet the needs of Sikh family members. Methodological limitations of the present study are highlighted and recommendations for future research offered.

*Keywords:* Sikh, family members, alcohol, alcohol services

## **12. Introduction**

### ***12.1 Engagement of Black and minority ethnic communities into alcohol services***

Evidence from quantitative and qualitative surveys strongly suggest that the prevalence of alcohol misuse within Black and minority ethnic (BME) communities is increasing in the United Kingdom (UK), with this increase predominantly being seen among South Asian and Afro-Caribbean communities (Rassool, 2006). At the same time, there is evidence indicating that BME substance misusers, especially those from South Asian communities, are underrepresented in treatment services within the UK (Rassool, 2006).

Orford, Johnson and Purser (2004) conducted a survey of 1684 males and females from a range of Afro-Caribbean and South Asian communities in Birmingham and Leicester on their levels of alcohol use. The study found that the majority of respondents believed that the most accessible help for alcohol misuse was through health centres and GP surgeries. Respondents reported that discussions with family members or close friends were not seen as an option, but the study did not address why this was. Through the use of semi-structured questionnaires the study also found that the use of friends for advice was very common among South Asian women. Finally, it was found that despite growing levels of alcohol use among second generation Sikh men in the UK; there remains a low level of awareness and perceived accessibility of sources of advice relating to alcohol (Orford, Johnson, & Purser, 2004).

Although not a recent study, Bola and Walpole (1997) suggest that a low level of engagement in alcohol services may be due to a lack of basic awareness of a range of health problems including substance use in BME communities. Adding to this finding, Thom, Lloyd, Hurcombe, Bayley, Stone, Thickett, Watts, and Tiffany (2010) argue that for a variety of reasons, BME communities experience difficulties in accessing services for alcohol misuse. The study found that although Equality Impact Assessments from the Department of Work and Pensions (which assess the effects of services on people in respect of disability, gender and racial equality) are a requirement of the 2000 Race Relations Amendment Act; it is not known how well their use addresses issues around alcohol, race and ethnicity (Thom et al., 2010).

Finally, Hurcombe, Bayley, and Goodman (2010) reported on drinking patterns among BME communities from the UK in a literature review of the past 15 years. The research evidence suggested that, within mainstream and specialist alcohol services, opportunities need to be explored to integrate the preferences of BME individuals. Furthermore, the research identified that service provision in alcohol services need to be flexible and adaptable to the changes in drinking patterns and attitudes among different BME communities.

### ***12.2 Alcohol consumption among Sikh men***

Research by Cochrane and Bal (1990) utilised a community survey of random samples of 200 Sikh, Muslim and Hindu men and 200 White English-born men, matched for age. Interviewed using a structured questionnaire containing a retrospective drinking diary, it was found that Sikh men in particular consume the highest level of alcohol between Sikh, Muslim and Hindu communities.



Evidence indicates that this high level of alcohol consumption among Sikh men is seen to be steadily rising with numerous associated psychological and physical health problems, including an increased rate of death due to liver cirrhosis (Bayley & Hurcombe, 2010; Bhui, Strathdee, & Sufratz, 1993; Douds, Cox, Iqbal, & Cooper, 2003).

Research by Kholsa, Thankappan, Mini, and Sarma (2008) found a positive relationship between a family history of alcohol consumption and the amount of alcohol consumed by Sikh students in India. Data collected over a two month period using structured and self-administered questionnaires from 536 final year university students with a mean age of 21 also found that Sikh men endorsed a higher level of drinking spirits than their Hindu and Muslim counterparts. This finding is also supported by Sandhu (2009) who describes a heavy drinking culture originating in the Punjab area of India which has continued among the Sikh community in the UK.

### ***12.3 Impact of addiction on family members***

Research by Copello, Templeton and Powell (2010) estimates that approximately seven million family members in the UK are affected by substance misuse of a relative. The impact of addiction on family members was investigated by Ray, Mertens and Constance in 2009. The study recruited 25,464 family members of someone with drug or alcohol dependence in the USA. These were matched to a family member of someone with asthma and diabetes. Logistic regression was used to determine whether the family members of someone with alcohol or drug dependence were more likely to be diagnosed with mental health problems than family members of someone with

diabetes and asthma. The study found that family members affected by those with an addiction are more likely to be diagnosed with a range of psychological problems including depression and trauma symptoms than a family member of someone with asthma and diabetes (Ray, Mertens, & Constance, 2009).

The impact of a person's alcohol dependence on their family member's mental health is further highlighted by the findings of Laslett, Room, Ferris, Wilkinson, Livingston, and Mugavin (2011). Surveys of 2622 randomly sampled Australian adults were completed by telephone. Results found that the presence of one problem drinker relative in a person's life was significantly associated with them experiencing anxiety and depression. Laslett et al. (2011) also found that if the problem drinker had had a negative effect on the family member's life, the adverse effect on their anxiety levels was much greater.

#### **12.4 *Rationale***

With regard to research focussing on family members in the Sikh community affected by alcohol dependence in the UK, only one study is prominent. Ahuja, Orford and Copello (2003) completed a mixture of semi-structured interviews and questionnaires with 24 female family members of Sikh men who had been identified as having alcohol dependence in the West Midlands. The study found that drinking habits of the Sikh men had a negative impact on the wives' and daughters' mental health. In addition to this, the study also found that in comparison to a White sample of females, the Sikh females had higher tolerance coping skills for their family member's alcohol dependence (Ahuja et al., 2003).

A further reason for conducting a study in this area of addiction is the limited research available on how community alcohol services work with members of a BME community. Research conducted by Banton, Johnson, Dhillon, Subhra and Hough (2006) on behalf of The Alcohol Research Forum distributed a questionnaire to numerous alcohol services across England exploring how they tailored their practice to support service users from BME communities.

The research found that there were relatively few services which were able to offer a comprehensive service to a range of BME communities. The study also found very few 'mainstream' or 'generic' service providers having the competence to deal with the specialist needs of BME communities. Overall, this piece of research found it almost impossible to state that an adequate level of service was being provided and was unconvinced that the requirements of the Race Relations Amendment Act were being observed (Banton et al., 2006).

Apart from the above study, there has been a lack of distinct research in this area. Therefore, it was felt that adopting a qualitative design for the present study would provide a source of rich and detailed data about engagement of Sikh family members of a person with alcohol dependence. Community alcohol services are at the frontline in delivering support to affected family members. Therefore, the present study aimed to investigate the experiences of staff from such services who have worked with Sikh families.

### **12.5 *Aims of the present study***

Specifically, the present study aimed to explore the experiences of staff in alcohol services providing support to Sikh family members affected by a relative's alcohol dependence.

The present study aimed to explore what staff perceived as barriers which may inhibit or prevent members of the Sikh community from accessing and engaging with alcohol services, as well as perceived factors that facilitate or promote engagement with services.

It was hoped that the findings from the present study may provide useful data for the future development of appropriate services for Sikh family members who may have been affected by the presence of an alcohol dependent relative in their life.

## **13. Method**

### **13.1 *Ethical Permission***

Prior to the present study commencing, ethical approval was sought and obtained from Coventry University ethics committee (see Appendix 4).

### **13.2 *Lead Researcher***

The lead researcher was a trainee clinical psychologist in his third year of a clinical psychology doctorate at Coventry University. The lead researcher was a 26 year old Sikh man from the West Midlands with an interest in the impact of alcohol dependence on families in Sikh communities and the experience of staff from alcohol services in providing the family members with support.

In order to explore his own responses to the experiences of staff working with Sikh family members affected by a relative with alcohol dependence, a bracketing interview was conducted between the lead researcher and a member of his research supervision team using the present study interview schedule (see Appendix 5) to facilitate discussion. The role of the bracketing interview was to enable a process of reflexivity about the researcher's own position and assumptions in order to bring further rigour and credibility to the process of analysing the data.

### **13.3 *Design***

A qualitative design methodology using semi-structured interviews was chosen for the present study as this was seen as an appropriate method to sensitively explore the topic of alcohol dependence. A qualitative design is an efficient way of enquiring into participant experiences and allows participants to openly share their views.

### **13.4 *Participants***

The present study attempted to recruit participants who worked in organisations which provided alcohol treatment for individuals with alcohol dependence and provided support for their family members. The organisations were all based in the West Midlands: Aquarius (Birmingham and Wolverhampton), The Recovery Partnership (Coventry) and Swanswell (West Bromwich). An inclusion criterion of the participants was that they had previous experience of working with members of the Sikh community affected

by alcohol dependence. An exclusion criterion was that all participants had to be able to speak English.

Basic demographic details of the participants were collected for the present study using a demographics questionnaire (see Appendix 6). Nine of the participants were female and one was male. They comprised of five Sikh, one Hindu, one Muslim and three White British individuals. The age of participants ranged from 26-55 and the mean number of years of experience working in an alcohol service was six years with four participants having over ten years of experience in the field. Seven of the participants were educated to degree level and three participants were educated to higher education level. Below is a table outlining the characteristics of the participants in the sample.

Table 1. Sample characteristics

<b>Participant</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnic Background</b>	<b>Years of Experience in field</b>	<b>Highest Qualification</b>
<b>1</b>	Female	46-55	Indian Sikh	2-5	Degree
<b>2</b>	Male	26-35	Indian Sikh	2-5	Degree
<b>3</b>	Female	26-35	Indian Sikh	1-2	NVQ
<b>4</b>	Female	26-35	Indian Hindu	2-5	A Level
<b>5</b>	Female	46-55	Pakistani Muslim	10-20	Degree
<b>6</b>	Female	46-55	White British	10-20	Degree
<b>7</b>	Female	26-35	White British	1-2	Degree
<b>8</b>	Female	26-35	White British	2-5	Degree
<b>9</b>	Female	36-45	Indian Sikh	10-20	Degree
<b>10</b>	Female	46-55	Indian Sikh	10-20	Diploma

### **13.5 Measures**

The present study used semi-structured interviews to gather in-depth data from participants. The use of semi-structured interviews enables the exploration of an individual's response to a research question. The semi-structured interview is a versatile method for collecting data and provides an appropriate format for discussing sensitive topics (Fylan, 2005).

An interview schedule (see appendix 5) was developed to facilitate discussion. The interview schedule consisted of open ended questions which aimed to explore the participants' views and experiences of working with members of the Sikh community affected by alcohol dependence.

### **13.6 Procedure**

Managers of three drug and alcohol services based in the West Midlands were contacted by telephone and given information in relation to the intended piece of research; including the rationale for conducting the present study. Following the initial contact made with managers, a copy of the participant information sheet (see Appendix 7) was sent by email to provide them with further information. Once managers had agreed that the study could take place using their staff members, they identified participants who met the inclusion criteria. A list of names were emailed to the principal researcher who then contacted each participant by telephone and arranged a time and date for the interview to take place. The employees were recruited on the basis that they had experience of working with family members from a Sikh community.

At the interview, participants were provided with information on the study in the form of a participant information sheet (see Appendix 7) and given the opportunity to ask any questions relating to the study. The participants were reminded that they were free to withdraw from the study at any point. Once queries about the study were addressed, written consent was sought (see Appendix 8) and interviews were conducted at the participant's place of work. The interview duration ranged from 15-60 minutes and was conducted in English. On completion of the interview, participants were allowed to ask any further questions and they were debriefed as to what would happen to the interview data. All participant interviews were audio recorded and transcribed verbatim by the lead researcher. Unique codes were used to replace personal identifiable information for protection of confidentiality.

### **13.7 Analysis**

Thematic analysis was conducted on the data gathered from the present study (see Appendix 9 for an example of data transcribed). Thematic analysis is a process of encoding qualitative information, focussing on identifying themes found in information that can go from describing possible observations to interpreting different aspects of the phenomenon being studied. Thematic analysis was chosen due to its capabilities of capturing the complexities of meaning within a textual data set. Thematic analysis is an approach which focuses on the ways that individuals make meaning of their experiences and the broader social context of those meanings (Borrell, 2008; Boyatzis, 1998; Guest, MacQueen, & Namey, 2012).



There were several stages involved in the Thematic analysis in line with guidance from Braun and Clarke (2006):

1. Transcribing data, reading and rereading the data, noting down initial ideas.
2. Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Checking the themes work in relation to the coded extracts and the entire data set, generating a 'thematic map' of the analysis.
5. On-going analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Selection of vivid, compelling extract examples, relating back to the research question and literature, producing a scholarly report of the analysis.

## **14. Results**

Ten semi-structured interviews with participants about their experiences of working with Sikh family members of a person with alcohol dependence were analysed using Thematic analysis. The interviews yielded five main themes related to: nature of familial support provided; attitudes to alcohol; lack of understanding; inter-generational differences; and targeting and tailoring of services. Within these main themes, 15 subordinate themes were also captured. These main and subordinate themes are summarised in Table 2 and are also presented in a thematic map (see Appendix 10). Each main theme and

subordinate theme is described below with examples of supporting transcript extracts.

Table 2. Summary of main and subordinate themes

<b>Main Themes</b>	<b>Subordinate Themes</b>
<b>Nature of familial support provided</b>	Family members as supportive
	Family members giving up
	Disproportionate female burden of care
<b>Attitudes to Alcohol</b>	Family members contributing to the problem
	Pro-social view of alcohol consumption
	Minimise the problem of alcohol
<b>Lack of Understanding</b>	Addiction
	Medical model
	Confidentiality
	Fear of being talked about by others
<b>Inter-Generational Differences</b>	Understanding addiction
	Expectations of an alcohol service
<b>Targeting and Tailoring Services</b>	Specific media outlets
	Outreach work
	Sikh temples

### **14.1 Nature of familial support provided**

Participants highlighted that Sikh family members offered different types of support for their alcohol dependent relative. The subordinate themes included; family members as supportive, family members giving up, and disproportionate female burden of care.

#### ***Family members as supportive***

The majority of participants identified the high level of support Sikh family members offered to someone with alcohol dependence in their family:

*“I have very little contact with other families, it’s mainly the individuals coming on their own whereas with the Sikh community I’ve found that, in my experience, they do want to be more involved, they do want to know what’s going on”. C1 L39*

Some participants perceived the size of the family structure as being important in this context:

*“I’ve noticed that there is a bigger family unit and it will be like erm external family members will offer support...” W3 L71*

#### ***Family members giving up***

Although the majority of participants described Sikh family members as important providers of support for their alcohol dependent relative, some participants had contrasting experiences. Three of the participants described how family members were not accessing alcohol services because they had given up supporting a relative with alcohol dependence:

*“...we come across relatives who are at the end of their tether by the time we see the dependent drinker and they do not want to be part of the supporting network...” Wb2 L47*

Some participants identified that for some Sikh family members, after providing support for a long time, they had eventually abandoned the alcohol dependent relative:

*“...they don't really care...they've given them so many chances to change but then when the drinker doesn't change their behaviour, they have to live on their own”. Wb1 L102*

### ***Disproportionate Female Burden of Care***

Within the support provided by Sikh family members for a person with alcohol dependence, it was perceived by participants that the majority of this support was carried out by female family members. In some instances, negative sequelae on the relative's wellbeing or mental health was highlighted:

*“I have come across wives off work cuz they can't actually keep up with everything, low morale...they themselves start experiencing depression, anxiety and panic attacks”. Wb2 L36*

Participant responses highlighted that for many female family members providing support, the expectation was for them to provide support in isolation without input from the extended family network:

*“...it's kind of like well, “you deal with it”, you know, “just brush it under the carpet then and get on with it”. Wb3 L65*

## **14.2 Attitudes to alcohol**

A main theme which featured in interviews with all participants was particular attitudes held by Sikh family members towards the use of alcohol in their community. This was described as family members contributing to the problem, a pro-social view of alcohol consumption, and minimising the problem of alcohol.

### ***Family members contributing to the problem***

Six participants identified how family members could add to the problem of a family member's addiction by not changing their own behaviour to support the alcohol dependent relative:

*"...Sikh families are like, "well you know what, it's tough, I'm still gonna drink, there's still gonna be alcohol in the house and they have to deal with it". W2 L49*

These participants also identified Sikh family members as contributing to the problem by providing alcohol for the problem drinker:

*"...I have seen it quite a lot where families, the mums are supplying the individual with alcohol..." W3 L65*

Lastly, participants highlighted how some family members contributed to the problem by pressuring the alcohol dependent relative to consume alcohol:

*"...when they are having parties or getting together even then the person makes excuses like, "I'm on medication", or, "I've been on detox, I don't drink", they are forced to just have one, "one won't hurt". Wb2 L64*

***Pro-social view of alcohol consumption***

All participants reported working with a Sikh culture where alcohol was a feature of the majority of social gatherings:

*"Sikh families you know it's acceptable, they have drink at weddings, celebrations, whatever, you know it's quite hospitable for Sikh families to offer you alcohol when you go and visit them, that's like a norm". B1 L118*

The participants in the present study highlighted how alcohol was heavily endorsed throughout the Sikh culture, including their music:

*"...like if you look at bhangra, DCS (Bhangra music group) are renowned and I hate em for it, "ik horr glassy chaktheer" (pick up one more glass)..." W1 L88*

Furthermore, participants perceived that those members of the Sikh community who did not drink, or did not drink to excessive amounts, would be negatively viewed:

*"If you go to a wedding and if you aren't droppin (drinking), so that culture needs to change so that's about if you're not a drinker, then you're frowned upon by other men". W1 L80*

***Minimise the problem of alcohol***

Five participants described Sikh family members as minimising the problem of alcohol in their family:

*"...ye it's the saying, "well they drink anyway, ok it's got out of hand, but it's not so much". B1 L28*

These five participants also perceived family members as minimising male drinking habits and attempting to justify the drinker's actions:

*“...“oh you know he drinks but he works as well”...“well who else doesn't drink, everyone drinks”. Wb1 L5*

### **14.3 Lack of understanding**

A main theme throughout interviews with participants was a general lack of understanding which Sikh family members held. This lack of understanding was related to knowledge of addiction, what alcohol services provided and the confidentiality of services which led to a fear of being talked about by others within the Sikh community.

#### ***Addiction***

Most participants found that when working with Sikh family members, there was a limited knowledge of alcohol dependence:

*“In family members, probably like the drinks as well, have no idea about the physical effects of alcohol, why people are drinking, the nature of addiction and also probably approaches to take to combat the problem”.*

*W1 L4*

The participants indicated that some Sikh family members lacked an understanding of appropriate ways to treat alcohol dependence. This in itself raised a number of concerns from participants as these approaches put the alcohol dependent relative at risk of numerous health problems:

*"...I've also become aware of them thinking they can just send them to rehab in I think India...there's a chance they could die as of course they're erm dehydrated..." W3 L36*

### ***Medical Model***

Also within the theme of a lack of understanding identified by participants when working with Sikh family members, there was also a tendency for family members to only understand the medical model of treatment for their alcohol dependent relative:

*"...he came with his mum and his sister...they wanted a detox and they wanted it now erm and they weren't really going to budge..." C2 L44*

It was found that when family members accessed an alcohol service; participants identified that they were more focussed on medical options to treat the alcohol dependent relative in their family:

*"...when we've told em about detox and that they, they get really interested in it all..." B1 L198*

Four participants identified that when some Sikh family members accessed alcohol services; they appeared to lack an understanding of the effectiveness of other treatment options such as talking therapies:

*"...they'll go, "well what you, you want me to do is just tell you how I feel but you're not gonna help me, you can't help me, give em a tablet"..." W2 L33*



### ***Confidentiality***

When working with Sikh family members of someone with alcohol dependence, four participants identified a community who held a lack of understanding in relation to the confidentiality of alcohol services:

*“...cuz confidentiality, data protection act is something that we need to explain in layman’s terms, in their language usually...” W1 L26*

This lack of understanding with regard to confidentiality led family members to expect information on their relative’s treatment to be readily available:

*“...you’d have to be quite strict at confidentiality cuz there’s an underlying assumption that the family would know everything and know what was going on.” C2 L9*

### ***Fear of being talked about by others***

Participants identified how a lack of understanding in relation to services being confidential led Sikh family members to fear being negatively talked about by other members of their Sikh community:

*“...I’ve seen a lot of Punjabi Sikh people are very afraid of gossiping. Cuz a lot of that goes on apparently they say, “oh I don’t want them gossiping, I know people will try and help but they’ll laugh behind my back”. B1 L106*

Participants highlighted how this fear of being talked about by others within their community, appeared to hinder Sikh family members’ desire to access an alcohol service for specialist support:

*"...we had a lot of people coming forward but of course again they're a bit kind of, unsure about it because they didn't want to be seen talking to alcohol awareness stands". W3 L160*

#### **14.4 Inter – Generational Differences**

From the views of five participants interviewed, differences were apparent between the inter-generations of Sikh family members who accessed services for support. This difference between inter-generations of Sikh family members was particularly prominent in their understanding of addiction and their expectations of an alcohol service.

##### ***Understanding Addiction***

Participants described first generation Sikh family members as holding different views of addiction to second and third generation Sikh family members:

*"Like parents born in India...that's a different ball game. They like confiscate the drink, it's still that lack of understanding about err addiction, "why they wanna drink then they've got everything"..."W1 L14*

Participants also expressed how strong beliefs held by first generation family members could not be changed and their focus was now on engaging with younger generations of Sikh family members:

*"...it's very difficult to change their mind set. I've noticed that's deeply engrained...if we can target the younger generation now we can help for the future". W3 L129*

### ***Expectations of an alcohol service***

A number of participants described a difference between what first generation Sikh family members expected from an alcohol service and how this compared to the needs of second and third generation Sikh family members of someone with alcohol dependence:

*“...the second generation, third generation, they are a bit more open in a sense, they, you know access services and so on. They want to be able to discuss what the issues are...” B2 L77*

Participants further perceived that second and third generation family members felt more comfortable seeking advice outside of their Sikh community:

*“...the second generation and third generation...wouldn’t wanna discuss their personal issues with a neighbour or someone down the road or with someone in the temple”. B2 L111*

### **14.5 Targeting and tailoring services**

Eight of the participants described a style of working in order to engage Sikh family members of someone with alcohol dependence in their service. This was through the use of specific media outlets, outreach work and liaising with local Sikh temples.

### ***Specific Media Outlets***

Seven participants reported using specific media outlets which catered for the Sikh community in the hope of raising awareness of addiction and promoting what their services provided:

*“Well we’ve been in various newspapers like Mann Jitt weekly, Asia Today to try and raise it, Express and Star, erm Punjabi Times”. W1 L117*

The seven participants described providing information in Punjabi to accommodate any language barriers and to ensure family members understood what their services provided:

*“We give out little wheels about alcohol use and bits like that...so they’ve got information in their own language that they can read...” B2 L504*

One participant in particular talked of taking part in an interview on a television channel specific for the Sikh community as a way of raising the awareness of alcohol use and what support services are available:

*“We have actually been on local radio and I am also taking part in a TV discussion very soon just making community members aware” Wb2 L18*

### ***Outreach work***

Responses from five participants suggested that alcohol services were being tailored for Sikh family members in the form of outreach work. This appeared to be specific to the location in which they worked with Sikh family members:

*“...we go out and do home visits if we have to, we set up their one to one appointments at the GP surgery...” B2 L487*

Participants described their services being tailored in order to provide a level of discretion for Sikh family members who did not want others to know that they were accessing an alcohol service for support:

*"...because there is no sign post saying alcohol it just says health centre it's actually successful in people coming forward". C1 L54*

### ***Sikh Temples***

In addition to utilising specific media outlets and providing outreach work as a way of engaging Sikh family members in their service, the majority of participants reported their alcohol service utilising local Sikh temples:

*"...most of the gurdwaras (Sikh temple of worship) are aware of our service...we kind of get old aunties coming up to us and saying, "well you know my son drinks and this is a problem"..." B2 L231*

Finally, some participants perceived that their service had become well established and well known to Sikh family members who attended a local Sikh temple:

*"...we've been through the temples as well, eventually they've started calling me the brain doctor". W2 L123*

## **15. Discussion**

An aim of the present study was to explore what staff perceived to be barriers which may have inhibited or prevented members of the Sikh community from accessing and engaging with alcohol services. It was hoped that the findings from the present study might provide useful data for the future development of appropriate services for Sikh family members of someone with alcohol dependence.

The findings from the present study are in line with findings from previous research in a number of ways (Cochrane & Bal, 1990; Kholsa et al., 2008; Rassool, 2006; Sandhu, 2009). Firstly, the present study highlighted the problematic nature of alcohol consumption in the Sikh community as identified by participants who experienced Sikh family members using alcohol on a regular basis and it being present in the majority of social gatherings. Participants perceived the Sikh community as one which held a general pro-social attitude towards alcohol and were known for consuming it in excessive amounts. These findings are also in line with the results of previous research which has identified that Sikh men in particular, encouraged heavier drinking among peers than members of other BME communities (Cochrane & Bal, 1990; Kholsa et al., 2008; Rassool, 2006; Sandhu, 2009).

Secondly, participants in the present study identified that Sikh family members they had come into contact with were very focused on the medical model of treatment with GPs in particular being highly regarded. This resulted in a number of Sikh family members expecting to gain support from the medical field rather than consider accessing specialist alcohol support services. This is in

line with previous research by Orford et al. (2004) who interviewed members of Afro-Caribbean and South Asian communities in Birmingham and Leicester on their use of alcohol and found that a number of respondents appeared to believe that the most accessible help was through health centres and GP surgeries.

A lack of understanding was a key finding in the present study. Participants identified how Sikh family members lacked a basic understanding of addiction, appropriate interventions to treat addiction and also a lack of understanding of the confidential nature of alcohol services. This key finding supports the observation of Bola and Walpole (1997) that a lack of basic understanding was a factor towards members of BME communities not accessing alcohol services for support.

The participants in the present study identified that there was a tendency for some family members to minimise the problem of alcohol which restricted engagement of Sikh family members in alcohol services. In addition to this, participants in the present study identified how a fear of being talked about by others in their community was a barrier in Sikh family members seeking support from alcohol services. This would suggest that the present study has highlighted a number of potential reasons why Sikh family members may be underrepresented in alcohol services as previously identified by Rassool, (2006) and Thom et al., (2010).

The present study also found that a large proportion of family members who provided support for an alcohol dependent relative in the Sikh community were female, indicating a likely disproportionate care burden on Sikh women. In addition, Sikh female family members were viewed as providing this support for

much longer than family members from other communities the participants had experienced working with. One participant in particular described her experience of female Sikh family members as having a higher tolerance towards their relative's alcohol dependence and as "not giving up". These findings are parallel to those of Ahuja et al. (2003) who identified that the majority of support for alcohol dependent Sikh men was being provided by their wives. The study by Ahuja et al (2003) also found that Sikh wives tended to have higher tolerance levels for addiction than wives providing support for an alcohol dependent person in a White community.

Uniquely, the present study has identified some of the ways in which alcohol support services are attempting to create a flexible service through outreach work, utilising specific media outlets to increase awareness of their services, and having a presence in Sikh temples as a way to engage Sikh family members in accessing their alcohol service for support. These methods of tailoring alcohol services found in the present study support and extend the findings of Hurcombe et al., (2010) who identified that specialist alcohol services needed to integrate the preferences of BME individuals and needed to be flexible in responding to the changes in drinking patterns and attitudes among these communities.

Overall, it is evident that the findings of the present study are in line with, and also build on previous research in the area of addiction and research into BME communities engaging in alcohol services. Not only has the present study identified the ways in which alcohol services have tailored their service to meet the needs of Sikh family members of someone with alcohol dependence, the



present study has provided new insights into the experience of staff members working with Sikh family members of individuals with alcohol dependence.

Firstly, the present study was able to capture how participants identified inter-generational differences between Sikh family members in relation to knowledge of addiction. Participants identified a challenge in changing the existing beliefs that first generation Sikh family members held about addiction which impacted on their expectation of alcohol services. This contrasted with participants identifying that second and third generation Sikh family members had more knowledge of addiction and therefore had different expectations of alcohol services.

The second new insight identified in the present study is the way in which participants perceived a difference of need between inter-generations of Sikh family members. Participants identified that, although first generation Sikh family members expected a medical model of treatment for an alcohol dependent relative, second and third generation family members were seeking alternative methods such as therapy. The study also found that second and third generation Sikh family members contrasted with first generation Sikh family members in wanting to gain support from outside of their community.

Finally, the majority of participants in the present study perceived Sikh family members as being supportive towards the person with alcohol dependence and this support was in contrast to the response of other family members participants had worked with; particularly White family members. The present study was able to highlight how this perception held by some participants is

being challenged through their experiences of Sikh family members who are now increasingly giving up supporting an alcohol dependent relative.

### **16. Implications for Alcohol Services**

The findings of the present study highlight a number of implications for alcohol services providing support for Sikh family members of individuals with alcohol dependence. The first implication is the prevalence of care burden on female Sikh family members. Participants in the present study identified a cultural expectation for female family members to support alcohol dependent individuals. In some circumstances, participants identified female family members being expected to provide this support in isolation from the extended Sikh community. This would indicate that alcohol services would benefit from being aware of how much burden is placed on females to care and support for a relative with alcohol dependence. Alcohol services need to provide assistance to female family members where necessary, which may include providing specific support groups or aiming to engage with female Sikh family members at an earlier stage of their relatives' alcohol dependence.

The findings from the present study have also highlighted how participants experienced Sikh family members as having a lack of understanding with regard to addiction and had little knowledge of what alcohol services could provide. This implies that alcohol services should take the appropriate actions to ensure that Sikh family members are becoming more aware of addiction. This might involve leaflet distribution, continuing to discuss alcohol issues through specific media outlets and beginning to educate the Sikh community at a younger age.

The present study has identified the ways in which alcohol services have tailored their role in order to support the needs of Sikh family members of someone with alcohol dependence. It is recommended that this tailoring should occur across the full range of different alcohol services available to Sikh family members of an individual with alcohol dependence. It is hoped that this would serve to tackle some of the barriers to accessing alcohol services and increase engagement from the Sikh community.

Implications for alcohol services were also provided by some participants in the present study who hoped to eventually provide specific information on what the expected journey of treatment would be if someone with alcohol dependence accessed their service. Two participants also foresaw the benefit of having more Sikh peer mentors within their alcohol service who could encourage other Sikh family members to receive similar support.

### **17. Limitations**

Although the present study has provided findings which both support and build on the existing knowledge base of Sikh family members affected by someone with alcohol dependence; a number of limitations exist. Due to the design of the present study, only ten participants were recruited. Although this provided the lead researcher with rich detail to be thematically analysed, the present study is limited by having a small sample size. For this reason, these findings cannot be generalised to the broader Sikh community based on the present study alone. Additionally, neither can the experiences of staff members from this present study account for all staff members who have experience of working with Sikh family members of someone with alcohol dependence.

A further limitation of the present study is that the majority of participants recruited were female. Although this high number of female participants may represent the workforce in this area of addiction, it limits our knowledge of the experience of male staff members when working with Sikh family members. Hence the findings can only represent the perceptions of a small female sample of staff members from alcohol services in the West Midlands.

A final limitation of the present study was the ethnic background of the participants recruited. The majority of participants were from a Sikh background which limits how much the experiences of these participants can be generalised to staff members from other ethnic backgrounds.

### **18. Further research**

Acknowledging the range of limitations identified in the present study, it is recommended that future research should aim to include participants from a range of locations in the UK.

Further research should also aim to conduct quantitative studies with larger sample sizes than the present study which may help to increase the generalisability of research findings.

As mentioned previously, the present study had a high proportion of Sikh female participants. Therefore, future research should aim to include more male participants. In addition, it may be helpful to include staff from a wider range of ethnic and cultural backgrounds than was achieved in the present study.

A unique finding of the present study was alcohol services' attempts to tailor their approaches to the specific needs of the Sikh community. Therefore, it

appears that future research could usefully measure the impact of the attempts alcohol services in the UK are making to engage family members from Sikh and other BME communities.

Finally, at present, the only study to investigate first hand experiences of Sikh family members of someone with alcohol dependence has been Ahuja et al. (2003). Therefore, it is imperative that future research aims to capture the detailed, first-hand experiences of Sikh family members affected by someone with alcohol dependence in the UK.

### **19. Conclusion**

This present study aimed to investigate the experiences that staff within alcohol services have had whilst providing support to family members of alcohol dependent individuals from the Sikh community. The present study highlighted familiar themes within participant experiences with regard to the nature of familial support provided by Sikh family members for someone who is alcohol dependent, the pro-social attitude held towards alcohol, a lack of understanding regarding addiction, available treatment options for addiction and the confidential nature of alcohol services. The participants also described inter-generational differences between Sikh family member's knowledge of addiction and their expectations of alcohol services. Lastly, the present study identified variations in how alcohol services are targeting and tailoring their services in specific ways to meet the needs of Sikh family members of someone with alcohol dependence.

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## **Chapter Three: The Sikh Lead Researcher**

Word count (including references) : 2,479

Article prepared for submission to Clinical Psychology Forum  
(refer to Appendix 3 for submission guidelines)

## **21.Summary**

This article presents the lead researcher's reflections on the process of conducting a piece of qualitative research. The article addresses reasons why the lead researcher conducted research in this area and how the research process impacted on the lead researcher's personal life.

## **22. Introduction**

This article presents my reflections on carrying out research which formed part of my doctoral thesis in clinical psychology. The empirical study carried out was an investigation into the views and experiences of staff members from alcohol services working with Sikh family members affected by someone with alcohol dependence. My reflections on the research process were captured through the use of a reflective diary that I maintained during my clinical psychology training. Throughout the process of conducting the empirical study a number of personal reflections emerged which are presented below.

## **23. Researcher curiosity**

As a 26 year old Sikh male, I had grown up in a culture where alcohol had been a feature at the majority of family gatherings throughout my life. I had been exposed to alcohol freely available at weddings and personally experienced peer pressure to consume a high level of alcohol when among family and friends. I had first-hand experience of seeing relatives struggle with their relationship with alcohol and was curious as to how Sikh family members were affected by someone with alcohol dependence.

The initial aim of my empirical study was to directly interview family members from the Sikh community affected by someone with alcohol dependence. It soon became apparent that this initial aim of the empirical study was hindered by the low number of Sikh family members accessing alcohol services. From this realisation, I felt that it was useful to explore why there were so few Sikh family members accessing alcohol services in the West Midlands.

## **24. Group membership**

When recruiting participants for my empirical study, I was surprised by the relatively high number of staff members in local services who were themselves from a Sikh background. I recall the participants being highly motivated to take part in the study and pleased that this type of research was taking place. The participants appeared to appreciate that research was being conducted which could potentially improve services for fellow members of a Sikh community who may be affected by someone with alcohol dependence.

During the present study I became aware of my own position as a Sikh male and how participants from a Sikh background were relating to me during interviews. Participants appeared to be able to openly express their views with me of working with Sikh family members affected by someone with alcohol dependence. The Sikh participants quite often ended their accounts with language such as, “as you’re fully aware” or, “as you know”. I sensed that the participants felt comfortable in talking about a culture that I was also a member of.

Not only did the participants from a Sikh background position me in their accounts of working with Sikh family members, but I noticed on occasions when Sikh participants would say things in Punjabi. I became very aware of how comfortable the participants must have felt in order to explain their experiences in Punjabi. Throughout this process I became curious as to the effect my ethnic background had on participants feeling comfortable enough to speak in Punjabi during the interviews. It is unclear whether participants were aware I was from a Sikh background, but the mere presence of an Asian lead researcher was

enough for participants to feel they could communicate in Punjabi. Termed as “group memberships”, research has sought to determine how a researcher’s personal characteristics shape the process of research. It has been found that these characteristics can impact on a participant’s willingness to respond authentically (Kram, 1988).

In contrast to a feeling of group membership with the Sikh participants, a sense of difference featured in two interviews with participants who were from a white background. These interviews were in contrast to ones I had conducted before as I sensed that these two participants were very aware that an Asian person was asking about their experience of working with a Sikh community. Although I cannot read too much into the difference experienced during these interviews, it made me question how comfortable participants are in divulging information depending on the researcher’s characteristics (Erdur, Rude, Baron, Draper, & Shankar, 2000). For some participants, my cultural background appeared to elicit their conversation to be free flowing. In other interviews, I felt that the participants were very aware of how they were describing their experiences of working with Sikh family members.

Throughout the interview process I attempted to control aspects of my “self” influencing participants by adopting two techniques offered by Kram (1988):

- 1) Systematic self-study: By keeping a personal diary throughout the research process, I was able to include the emotional reactions I had to events being explored and my internal thoughts.

2) Creating a research team: for this piece of research to be successful, I had a research supervision team including two experienced clinical psychologists. This allowed me to receive on-going feedback throughout the research process and facilitated discussions of study design, data collection and analysis.

However, on reflection, I was completely unaware how my cultural background was potentially influencing the research of my empirical study. Throughout the last three years as a trainee clinical psychologist, I have never felt that my cultural background was influencing therapy with clients. I have on occasion been aware that my age and gender may have impacted on therapeutic relationships, but not in relation to the fact that I was an Asian trainee clinical psychologist. Through the process of interviewing participants for the present empirical study, I was suddenly made acutely aware of how my Asian background was unintentionally influencing the interviews taking place.

### **25. Similarity of experiences**

As I progressed with my research and a number of interviews had been conducted, there were a number of similarities between experiences of Sikh family members affected by someone with alcohol dependence which participants spoke of, and my own personal experiences. I recall one particular interview which had taken place which made me feel as though my own personal story had been captured by the participant. Throughout the interview I could see a timeline of events being described which were similar events I had also experienced.

The events described were related to the attempts family members had made to control an alcohol dependent's addiction. This attempt to control the addiction was done by confiscating the alcohol and questioning why they would want to drink alcohol when "they have everything". As participants described such events, I was reminded of times in my own personal life where relatives had posed those exact same questions, and poured alcohol down a sink in an attempt to stop a family member from drinking it. I was also reminded of family gatherings where extended family members would not recognise when a relative's alcohol consumption had become excessive. This would lead to a struggle of trying to control the amount of alcohol consumed by a family member and ensure that other family members were not forcing it upon them.

This similarity of what Sikh family members had experienced through the eyes of the participants and my own life experiences, highlighted how much of an impact living with someone with addiction can have on a family. This similarity was further emphasised by the number of Sikh family members, who had had similar experiences to me. Previous to this, I had always assumed that giving up support for a family member who was alcohol dependent was very rare in the Sikh community. However, as I heard accounts of participants coming into contact with people who were alcohol dependent without a support network, it made me realise that many other family members arrived at a point in their life where they had given up support.

As a result of this, I took particular care to be reflexive about my own personal experiences and to make efforts to limit my own subjective position unduly influencing my analyses of the data. This was aided by having a bracketing

interview and a reflexive discussion of my own researcher position to try to bracket off subjective biases.

## **26. My own personal barriers**

The present study has identified how some Sikh family members have struggled with supporting a relative who is alcohol dependent. Whilst struggling to cope, the family members have not always accessed alcohol services for support. This lack of engagement by Sikh family members in alcohol services made me reflect on why I myself hadn't accessed services for support. As a trainee clinical psychologist I felt I was reflective and psychologically minded to acknowledge when outside support was necessary. I encouraged friends and family to access mental health services when they felt they were struggling with mental health issues and I talked positively of the role therapy could have in improving people's lives.

From the role I had in the present piece of research, I realised that I had once had my own barriers to accessing alcohol services which were similar to the barriers that participants had encountered when working with Sikh family members. In reflection, I think the biggest barrier I faced which stopped me from accessing alcohol services for support was not having an understanding of addiction. I had a limited knowledge of the causes of addiction, the reasons why people turn to alcohol and the appropriate treatment methods to manage an alcohol addiction.

Alongside this lack of knowledge, I also held a barrier in thinking that my family alone could cure a relatives' alcohol dependence. I was reminded of all the past



attempts made to minimise the risk of a relative abusing alcohol. This included removing all alcohol from family homes, limiting how much the alcohol dependent relative mixed with other families who consumed alcohol, and behaving in ways which would alleviate the family member of any stress which may trigger their need for alcohol.

As I reflect on the, “home-made” interventions I attempted, I am amazed at my own naivety in thinking those methods would work. I feel fortunate enough to have a better understanding of addiction due to my role as a trainee clinical psychologist. However, conducting the present study has made me realise how many other Sikh family members continue to have a lack of understanding with regard to alcohol dependence. For some family members, they continue to try their hardest to support their alcohol dependent family members through the use of what I can only describe as, “home-made” interventions.

## **27. Course of action**

Following one of the last interviews conducted for the present empirical study, I became aware of how long alcohol dependent Sikh men could spend consuming alcohol prior to accessing alcohol services for support. For many alcohol dependent Sikh men, the time in which they finally accessed alcohol services was often too late and a hospital admission was the only appropriate form of treatment available which saddened me.

I recall feeling encouraged to make one last attempt to engage one of my family members in accessing an alcohol service for support with their alcohol dependence. I was aware that this family member was clearly in a pre-

contemplation stage of change. The family member had no intention of changing their unhealthy behaviour and was unaware of the need to change. Furthermore, the family member in question appeared to minimise how severe their alcohol dependence was and claimed that they had control over it (Patterson & Nochajski, 2010).

Whilst I listened to an appointment being arranged, I was very pessimistic that this family member would attend. I was reminded at this point of how many participants had described Sikh family members wanting the problem drinker to access services more than the drinker themselves and here I was; one of those Sikh family members, in one last ditch attempt to gain some specialist support for an alcohol dependent family member.

### **28. The last ditch attempt**

Four months since my somewhat haphazard intervention took place; the family member in question has continued to access numerous alcohol services for support and guidance on their alcohol dependence. This has included being prescribed medication, attending group therapy and partaking in general alcohol awareness sessions. Although it has taken a number of years for this engagement in alcohol services to occur and be maintained; it is hoped that this family member can begin to address their chaotic relationship with alcohol and can begin to benefit from specialist support.

In reflection, I feel as though it was conducting these interviews which were the catalyst for me attempting to engage a family member in accessing an alcohol service for support with their alcohol dependence. Prior to conducting the

study, I had always seen myself as a family member who no longer provided support and had, “given up” to protect myself from being affected by their alcohol dependence. However, conducting this study has challenged my existing beliefs on my role in providing support and I feel that in my own way, I fall into the category of a Sikh family member who somewhere somehow, doesn’t give up.

## **29. Conclusion**

Overall, I am surprised by the impact conducting this piece of research has had on my personal life. At times it was mentally tiring, but in summary, it was a process that I am thankful I went through. Gilbert (2001) for example, proposes that there is often an emotional impact when conducting qualitative research but that our research efforts are enriched by a personal and emotional engagement in the research process. Personally, the present study has instilled in me a desire to communicate to other members of my Sikh community who may be affected by alcohol dependence that there is help available.

Furthermore, conducting this research has made me aware that the drinking culture which surrounds the Sikh community needs to change, and for this change to occur, Sikh family members need to access formal alcohol services and alcohol services need to target and tailor their services in ways that serve to increase their effectiveness in supporting individuals of Sikh origin.

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## **APPENDICES**

## Appendix 1: Instructions for authors Journal of Dementia

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We value your feedback to ensure we continue to improve our author service levels. On publication all corresponding authors will receive a brief survey questionnaire on your experience of publishing in *Dementia* with SAGE.

### **10.4 OnlineFirst Publication**

*Dementia* offers OnlineFirst, a feature offered through SAGE's electronic journal platform, SAGE Journals Online. It allows final revision articles (completed articles in queue for assignment to an upcoming issue) to be hosted online prior to their inclusion in a final print and online journal issue which significantly reduces the lead time between submission and publication. For more information please visit our Online First Fact Sheet.

## **11. Further information**

Any correspondence, queries or additional requests for information on the Manuscript Submission process should be sent to the Editorial Office at [dem.pra@sagepub.com](mailto:dem.pra@sagepub.com).

## Appendix 2: Instructions for authors on Journal of Ethnicity in Substance Abuse

The *Journal of Ethnicity in Substance Abuse (formerly Drugs & Society)* presents rigorous new studies and research on ethnicity and cultural variation in alcohol, tobacco, and other drug use and abuse. The research is drawn from many disciplines and interdisciplinary areas in the social and behavioral sciences and helping professions. The journal is an important addition to current addiction studies education, providing background knowledge and intervention techniques to educators, policymakers, and practitioners working with today's diverse client population. The Journal of Ethnicity in Substance Abuse is an international forum for culturally competent strategies in individual, group, and family treatment of alcohol, tobacco, and other drug abuse. The journal also offers strategies for program development and evaluation, prevention programming, and harm reduction strategies that are ethnically or culturally appealing. This journal systematically investigates the beliefs, attitudes, and values of substance abusers, searching for the answers to the origins of drug use and abuse for different populations. The journal has several regular features, such as "In Brief," which consists of news articles significant to ethnicity. The journal also publishes letters, reviews of print and nonprint media, and listings of significant Web sites for further investigations.

### Manuscript submissions:

*Journal of Ethnicity in Substance Abuse* receives all manuscript submissions electronically via its ScholarOne Manuscripts site located at <http://mc.manuscriptcentral.com/wesa>. ScholarOne Manuscripts allows for rapid submission of original and revised manuscripts, and facilitates the review process and internal communication between authors, editors, and reviewers via a web-based platform. ScholarOne technical support can be accessed at <http://scholarone.com/services/support>. If you have any other requests, please contact Peter Myers, Editor-in-Chief, [atjourethsubabuse@gmail.com](mailto:atjourethsubabuse@gmail.com).

Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. As an author you are required to secure permission if you want to reproduce any figure, table or extract text from any other source. This applies to direct reproduction as well as to reproduction of photographs and artwork, manuscripts, accepted All source). copyrighted a from substantially derives which table or figure new created have you (where reproduction? derivative>

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not

more than 100 words. Avoid abbreviations, diagrams, and reference to the text in the abstract. Please consult our guidance on keywords here .

## **References**

APA references, citations, and general style of manuscripts should be prepared in accordance with the APA Publication Manual, 6th ed. Cite in the text by author and date (Smith, 1983) and include an alphabetical list at the end of the article.

Examples:

Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. *Archives of Sexual Behaviour*, 7(6), 417-427.

Book: Millman, M. (1980). *Such a pretty face*. New York: W. W. Norton.

Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), *Ageing in the 1980s* (pp. 239-252). Washington, DC: American Psychological Association.

## **Illustrations**

Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- Sized to fit on journal page
- EPS, TIFF, or PSD format only
- Submitted as separate files, not embedded in text files

## **Color Reproduction**

Color art will be reproduced in the online production at no additional cost to the author. Color illustrations will also be considered for the print publication; however, the author will bear the full cost involved in color art reproduction. Please note that color reprints can only be ordered if the print reproduction costs are paid. Print Rates: \$900 for the first page of color; \$450 for the next 3 pages of color. A custom quote will be provided for authors with more than 4 pages of color. Art not supplied at a minimum of 300 dpi will not be considered for print.

## **Tables and Figures**

Tables and figures (illustrations) should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet.

### **Proofs**

Page proofs are sent to the designated author using Taylor & Francis' Central Article Tracking System (CATS). They must be carefully checked and returned within 48 hours of receipt.

### **Reprints and Issues**

Authors from whom we receive a valid email address will be given an opportunity to purchase reprints of individual articles, or copies of the complete print issue. These authors will also be given complimentary access to their final article on *Taylor & Francis Online*.

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Visit our Author Services website for further resources and guides to the complete publication process and beyond.

## Appendix 3: Notes to contributor for Clinical Psychology Forum

*Clinical Psychology Forum* (CPF) welcomes contributions which are **original, innovative, authoritative and of interest to the membership of the Division**. We aim to publish a variety of contributions ranging from personal reflections on clinical practice to critiques of current health policy, innovations in service development, and audit and research studies.

From time to time we commission **reviews and Special Issues**. We also act as a major communication channel between the DCP and its subsystems, and its membership by publishing a monthly DCP Chair's Column, DCP Update and various regular columns and features.

We also publish **correspondence** either regarding articles published within CPF or around issues of general interest to the membership.

Articles submitted to CPF will be sent to members of the editorial collective for refereeing. Reviewers will assess each contribution in relation to the manuscript's clarity and economy of expression; its critical and analytic stance; whether its original or innovative; and, where appropriate, that methods and results are well described, methodological sound and any conclusions drawn are valid. Overall, articles must be relevant and of interest to the profession (see *Advice from the Editorial Collective* below, originally published in CPF 227, November 2011, p.9). The reviewer shall then communicate directly with the authors.

Articles of **1000-2500 words** including references are welcomed. If you feel an article longer than 2500 words is justified please state the reasons in an accompanying letter and these will be considered by the reviewer.

Contributors are asked to use language which is **respectful and psychologically descriptive** rather than medical, and to **avoid using devaluing terminology** (i.e. avoid clustering terminology like 'the elderly' or medical jargon like 'patients'). In addition, language should conform to the Society's guidelines on non-sexist or discriminatory terminology. We acknowledge that language is context specific and that occasionally authors may wish to justify the use of particular terms commonly adopted within specific contexts. Please include any such qualifications within an accompanying footnote.

Please **email one electronic copy and post one hard copy** of your contribution to the CPF administrator, Sue Maskrey (details below). Please ensure that your **contact details (email and current postal address), current employer and job role** are included in case the editors need to contact you. Please do not submit articles directly to the Editor.

### Other points to consider

- All contributors should read the FAQs about publishing in *Clinical Psychology Forum* before submitting a manuscript.

- When sending copy, make sure it is **double-spaced**, in a **reasonable sized font** (no less than 11 point) and that all **pages are numbered**.
- Include a **40-word summary** (maximum) at the beginning of the paper.
- Include the **first names of all authors**, give their **job titles and affiliations**, and remember to give an **email address** and **full postal address** for correspondence.
- Please include a **word count** at the end (including references).
- Spell out all **acronyms** the first time they appear.
- Give references in the format set out in the Society's Editorial Style Guide (see below). If a reference is cited in the text, please make sure it is in the list at the end.
- Do not include **tables and figures** unless they are **essential** and save space or add to the article. All figures should be in **black and white** and easily reproducible.
- Ask readers to **request a copy** of your **questionnaire** from you rather than include the whole of it in the article.
- We reserve the right to shorten, amend and hold back copy if needed.



## Appendix 4: Coventry University Ethical Approval

### REGISTRY RESEARCH UNIT

### ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

**Name of applicant:** Nick Johl.....

**Faculty/School/Department:** [Health and Life Sciences] HLS Clinical Psychology

**Research project title:** Exploring alcohol services' staff experiences of providing support services for relatives of alcohol dependent individuals from the Sikh community

Comments by the reviewer

#### 1. Evaluation of the ethics of the proposal:

As before, this is a good proposal and there is greater clarity and detail regarding the procedure. The inclusion of a demographic questionnaire is noted.

#### 2. Evaluation of the participant information sheet and consent form:

Both the PIS and PCF are much improved and, as above, they offer greater clarity and detail than previous submission. The improvements with regard to both sheets are noted. There are a number of minor amendments which would be helpful to address and they are:

1) With regard to the participant information sheet it may be helpful to clarify that the interview will be conducted with the principal researcher.

2) The PIS states that participants may become distressed during the interview which is helpful, but goes on to suggest that there may be other risks/burdens. I wonder if it might be helpful, if there are, to outline what these might be?

3) With regard to the consent form, it would be helpful to include a specific point stating "I agree to participate"

**3. Recommendation:**

(Please indicate as appropriate and advise on any conditions. If there any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

<input type="checkbox"/>	Approved - no conditions attached
<input checked="" type="checkbox"/>	Approved with minor conditions (no need to re-submit)
<input type="checkbox"/>	Conditional upon the following – please use additional sheets if necessary (please re-submit application)
<input type="checkbox"/>	Rejected for the following reason(s) – please use other side if necessary
<input type="checkbox"/>	Not required

**Name of reviewer:** Anonymous .....

**Date:** 24/10/2012

## Appendix 5: Interview Schedule

### Interview Schedule

**Title of the study:** Exploring alcohol services' staff experiences of providing support services for relatives of alcohol dependent individuals from the Sikh community.

**Participant Name:**

**Date:**

**Venue:**

**Time:**

**Introduction:**

The principal researcher will discuss the purpose of the study with the participant, which is to explore their experiences of working with Sikh families who have been affected by alcohol misuse.

**Conduct of interview / main questions.**

1. What has your overall experience been of working with relatives / family members of alcohol dependent individuals from the Sikh community?
2. In your experience, what are the main support needs of relatives / family members from the Sikh community who may be living with an alcohol dependent person?
3. How have the relatives / family members that you have worked with responded to your efforts to provide them with support?  
*Prompt: are there any similarities to/ differences from family members, from other communities you have worked with?*

4. a. What, in your opinion are the barriers which inhibit or prevent Sikh relatives / family members from accessing alcohol services for support or engaging with such services?  
  
b. (If barriers to engagement have been identified, follow-up question is,) In what way do you think these barriers to engagement can be changed or minimised?
5. When engagement from family members of an alcohol dependent person has been good, what do you think has facilitated this?
6. What does your service do at present to facilitate engagement from members of the Sikh community affected by alcohol misuse?
7. In your opinion, are there any changes that your service could make to promote greater engagement of relatives and family members of those with alcohol dependence from the Sikh community?  
  
*Prompt: (if yes), could you say a bit more about this?*
8. Is there anything else you wish to add that you feel may be relevant?

**Conclusion:**

This entails a debriefing session, asking the participant if there is anything else they would like to add and asking if they are happy with the interview. The interviewer can answer any questions in this section and ensure the participant understands the purpose of the study and what will happen with the findings.

The participant will then be thanked for taking part in the study.

## Appendix 6: Demographics Questionnaire

### Demographics Information Questionnaire

**Title of the study:** Exploring alcohol services' staff experiences of providing support services for relatives of alcohol dependent individuals from the Sikh community.

- 1. Please write your job title below.**

---

- 2. Please indicate your gender by circling one of the options below.**

Male

Female

- 3. Please indicate your age by circling one of the options below?**

18-25

26-35

36-45

46-55

56-65

Over 65

- 4. Which ethnic group do you belong to? Please place a tick in the relevant right-hand box (giving details if you tick the 'other ethnic group' box).**

White	British	
	Irish	
	Other White	
Mixed	White and Black Caribbean	
	White and Black African	
	White and Asian	
	Other Mixed	
Asian or Asian British	Indian	
	Pakistani	
	Bangladeshi	
	Chinese	
	Other Asian	
Black or Black British	Caribbean	
	African	
	Other Black	
Other ethnic group	Other ethnic group (please specify)	

- 5. What is the highest level of educational qualification that you achieved (e.g. No qualification, 'O' levels, GCSE's, 'A' levels, Degree etc.). Please indicate this by writing your answer here:** \_\_\_\_\_

\_\_\_\_\_

**6. Please indicate your marital status by placing a tick against the option that best describes your current circumstances.**

Single (never married)	
Have a partner (but not married)	
Married	
Re-married	
Separated (but still married)	
Divorced	
Widowed	
Other (please specify)	

**7. Please indicate your religious affiliation (if any) by circling one of the options below?**

None

Catholic

Protestant

Church of England

Jewish

Sikh

Muslim

Hindu

Other (please describe).....

**8. Please indicate how long have you been working in drug and alcohol services for by circling one of the options below?**

Less than a year

Between 1 and 2 years

Between 2 and 5 years

Between 5 and 10 years

Between 10 and 20 years

More than 20 years

**Thank you for taking the time to complete this questionnaire**



## **Appendix 7: Participant Information Sheet**

### **Participant Information Sheet**

**Title of the study:** Exploring alcohol services' staff experiences of providing support services for relatives of alcohol dependent individuals from the Sikh community.

I would like you to take part in a research study. Before you make your decision, I would like to give you some information as to why I am doing this research study and what your role would be if you decide to take part.

#### **What is the study about?**

The proposed study will conduct interviews with staff from alcohol services who have worked with members of the Sikh community. The study aims to explore participants' experiences of working with Sikh families who have been affected by alcohol misuse. It is hoped that the findings from this study may have applications in the future development of appropriate services for Sikh family members who may have been affected by the presence of an alcohol dependent relative in their life.

#### **Why have I been invited?**

You have been identified as a staff member working in an organisation that provides treatment and support for family members affected by alcohol misuse and who may have experience of working with members of the Sikh community.

#### **What does taking part involve?**

The study will involve completing a demographic questionnaire and signing a consent form prior to the interview taking place. Once these forms have been completed, you will be interviewed by the principal researcher. The interview will take approximately 30 to 60 minutes to complete and will take place at the alcohol service in which you work. The interview will be audio recorded so the data can be analysed. You will be asked questions related to your experiences of working with Sikh family members who have accessed alcohol treatment services for support.

### **Will my information be confidential?**

Your interview will be audio recorded. Your data throughout the study will be treated as confidential and all information provided throughout will be made anonymous. Any identifying data will be removed to ensure confidentiality. The audio data will be kept on a password protected recording device that only the principal researcher will have access to.

Your answers during the interview will be transcribed in typed form and printed onto paper in order to be analysed. Quotes will be extracted from the typed transcript and presented in the results section of the study. The typed data will be kept on a password secure computer that only the principal researcher will have access to.

Once all of the interviews have been transcribed, the digital recordings will be erased. All other data will be kept secure in a locked cabinet that only the principal researcher will have access to. Once the study has taken place, all forms of data will be securely stored at Coventry University for 5 years before being destroyed.

### **Do I have to take part?**

Taking part in the study is entirely voluntary. If you agree to take part you will have to sign a consent form. You are free to withdraw your data at any time, without giving a reason up until 31/01/2013 when analysis of the data will commence. If you decide to withdraw from the study, please contact the Principal Researcher (Nick Johl) by telephone or email to request this.

### **What are the possible benefits and risks of taking part?**

It is anticipated that the information gained from this study will aid in understanding the experiences of staff working with Sikh families affected by alcohol misuse and may contribute to our understanding of the potential barriers faced by members of the Sikh community in accessing and engaging with alcohol services for support. It is also hoped that results from this study may help inform the development of interventions to increase access and engagement from Sikh family members affected by a relative's alcohol dependency.

Although we consider it to be unlikely, it is possible that taking part in the study may cause you some distress (e.g. when answering questions about your work role). If this were to occur, it is suggested that you seek support from an appropriate source, such as your GP.

**Contact details**

For further information, please contact the Principal Researcher, Nick Johl, using the following contact details:

Email address: [john@uni.coventry.ac.uk](mailto:john@uni.coventry.ac.uk)

Telephone: 024 7688 8328

Postal address: Nick Johl, Clinical Psychology Doctorate (JSG24), Faculty of Health and Life Sciences, Coventry University, Priory Street, Coventry CV1 5FB.

**Supervision**

This research is being conducted as part of a clinical psychology doctorate course at Coventry University, under the supervision of Dr Tom Patterson (Senior Lecturer, Coventry University) and Dr Katherine Simons (Senior Lecturer, Coventry University). If you have any concerns about this study, please contact Dr Tom Patterson at Coventry University on Telephone: 024 7688 8328 or email [t.patterson@coventry.ac.uk](mailto:t.patterson@coventry.ac.uk).

Finally, if you would like to receive a summary of the results, available after completion of the study, please indicate this in the relevant section of the consent form.

Thank you for taking the time to read this information and for considering taking part in the study.

Nick Johl

Principal Researcher

## Appendix 8: Consent Form

### Consent Form

**Title of the study:** Exploring alcohol services' staff experiences of providing support services for relatives of alcohol dependent individuals from the Sikh community.

**Instructions:** Please read the statements below and tick the boxes to indicate your agreement. Then please sign and date the form at the bottom of the sheet.

I have read and understood the information in the participant ☐  
information sheet.

I give permission for my interview to be audio recorded. ☐

I understand that the audio recording will be stored securely ☐  
and treated confidentially.

I give permission for the audio recording of the interview to ☐  
be transcribed and used as part of the research.

I understand that the transcribed information will be stored ☐  
securely and treated confidentially.

I agree to participate in this study.

☐

I understand that my participation is voluntary and that I am

☐

free to withdraw from this study until the 31<sup>st</sup> of January 2013  
at any time without giving a reason.

Signed: \_\_\_\_\_

Print Name: \_\_\_\_\_

Date: \_\_\_\_\_

*If you would like to receive a summary of the results of this study once it has been  
completed (1<sup>st</sup>, August 2013), please indicate by ticking this box:*

☐

## Appendix 9: Example of Transcribed Data

75 Can you tell me a bit more about what the education might be about?

76 *Awareness of physical effects of alcohol*  
Err raising the awareness of what alcohol harm, psychical and mental health and how the person is  
77 affected you know, especially when you become a dependent drinker you know, that's sort of  
78 around there, and really physical health about the liver, kidneys all the kind of things is affected and  
79 the emotional wellbeing and health in why's he behaving, why he moody, you know stuff like that  
80 it's all round I think they need to be educated on

81 How have the relatives / family members that you have worked with responded to your efforts to  
82 provide them with support?

83 *(Younger generation welcome support from services) P.O will accept their drinking is a problem.*  
I think they've been quite welcoming, erm the younger generation especially cuz erm, they'll say,  
84 "oh I didn't realise you know, that I was drinking those many units and didn't realise how harmful it  
85 was", it's like opening their eyes and the older generation, you know when you go through the cycle  
86 of change with them having the change the behaviour, they find that quite useful erm you know,  
87 preventive measures, erm when you, "well how are you going to reduce your drink", Do you know,  
88 "well I always go, to the pub", you know and you'll say, "well you have to try not to go so many  
89 times a week", "but how am I gonna change that, that's my social networking", like sort of telling  
90 them what their triggers are you know they don't realise *teaching me P.O about their choices in regards to drinking*

91 And how have the family members of the alcohol dependent person responded to your support?

92 *Informed of choices*  
Erm I think I think most of the time they've sort of welcomed it cuz it makes them understand what's *FM end of their tether, can do something for themselves*  
93 going on ye and it also gives them options ye, gives them options to what else is available to them.  
94 So you know if they're at the end of their tether and they're suffering with dv and that, then they  
95 can always say there's other services like women's aid and they can get support and obviously  
96 there's children and by law we have to inform you know we've and that can be quite difficult at  
97 times but we've got to do it but if they come and disclose there's children and he's drinking around  
98 them then you know, so we have to then get social services involved and that doesn't always go  
99 down well but then you've built up the trust with them, you know, and that's maybe one of the  
100 reasons why they hide it *Social services have to be involved if children at risk*

101 Can you tell me a bit more about that?

102 About the children?

103 Well why the community might hide it?

104 *Fee of being gossiped about.*  
*Life* *Community hide it to keep family together.*  
They might hide it because they don't want to split the family up, they will suffer with dv and  
105 whatever as to keep the family together, they don't want the shame of what's happening to them or  
106 the family. Erm the stigma, I've seen a lot of Punjabi Sikh people are very afraid of gossiping? Cuz a  
107 lot of that goes on apparently they say, "oh I don't want them gossiping, I know people will try and  
108 help but they'll laugh behind my back", you know that sort of thing, I think they get paranoid at  
109 times you know, with that sort of thing, erm because I'm not from that culture you know because  
110 I'm a Muslim I think they seem to offload to me quite a bit and I do understand their cultural issues,  
111 I'm Punjabi anyway. Although I might not be Sikh but I do know, living in the community, what goes  
112 on. So it's just reassuring them, "look, you know if you really want help, you need to be doing things

*FM comfortable speaking to non Sikh staff.*



Stuff have to build trust before Sikh community opens up.

113 safeguarding yourself and the kids", so it and you have to build up that trust with them before they  
114 open up to you ye

115 Are there any similarities to/ differences from family members, from other communities you have  
116 worked with?

Muslim community disown P.D. Alcohol is acceptable in Sikh community

117 I think the Muslim community, ye usually the person been disowned because it's just not openly Muslim  
118 acceptable erm compared to the Sikh families you know its acceptable, they have drinking at P.D.  
119 weddings, celebrations whatever erm with Muslims they do drink but never openly, ye it's never disowned  
120 offered in house like you do, you know it's quite hospitable for Sikh families to offer you alcohol to set  
121 when you go and visit them, that's like a norm but with Muslims I think a lot of the guys get examp  
122 disowned erm and what they do is that by the families disowning them, they try to set an example for a  
123 for the others in the family, the younger siblings perhaps or so, it is a shame, but the pressure are a Muslim  
124 little different Muslim drinker disowned by family

125 Ok, can you tell me a bit more about the pressures being different?

Muslims won't even speak about Alcohol.

126 The pressure is like for Muslims it's like they don't even wanna go there, discuss something hidden  
127 banned, you shouldn't be doing it, stop it at that, you know. So it's about they're not coming forward Sikh M  
128 to get the information, the education there perhaps needed, and we know it does go on in the open dis  
129 community as well, especially within the younger generation you know, it's the peer pressure in discoun  
130 colleges and whatever, erm they are aware, erm so it's a little bit different them opening up to us or drink is  
131 we going in you know if you go to a Sikh family or speak to them in the guruwaras, "do you know from  
132 anybody drinking", they'll say, "yes", with Muslims they say, "no", (laughs) even if they are aware, Muslim  
133 they just don't wanna admit that that want anything to do with so. Sikh's will identify Problem  
drinker

134 And are there any similarities?

Putting up a front to their community. Muslim  
Asian families peer share

135 I think this fact about shame again, that stigma around shame it's the same with the Asian families  
136 but perhaps not so much with white British and other nationalities, but with Asians they think about  
137 shame because I think they put a front up like you know as a family, set examples for others, "we're  
138 doing well, the kids are doing well", so I think the stigma around shame?

Asian families put a front on to other families

139 Can you tell me a bit more about why that might not be in English cultures?

140 Erm in English culture I think you know it's people are more independent, living their own lives, Collectivist culture (upbringing)  
141 they're not so much a joint family. Ye if somebody's got problems and it's them and their partners,  
142 no others get involved much, you know what I mean? I think it might be to do with that, whereas  
143 Asians seem to be more tight knit communities, everybody knows everybody, its business what's  
144 going on you know (laughs) whose got married, who's got kids and all the rest so I think it's to do  
145 with that really, maybe a bit more nosier I don't know but its more you know, tight knit

146 What, in your opinion are the barriers which inhibit or prevent Sikh relatives / family members  
147 from accessing alcohol services for support or engaging with such services?

148 Family members?

149 Ye

Asian families able more notice in other peoples business

## Appendix 10: Thematic Map

